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ABSTRACT

The document describes a study on autism in Illinois designed to review relevant legislation, conduct on site visits to a number of programs, collect information about prevalence rates, describe the existing system, identify service deficits and gaps, develop a model comprehensive continuum of services from conception through adulthood, and formulate a statement of actions necessary to implement the model. Chapters address the following topics (sample subtopics in parentheses): description of the population (historical overview, current theory on diagnosis and etiology, Illinois population, prevalence rates); current service system (characteristics of the system, the Department of Mental Health/Developmental Disabilities, the public education system, joint responsibilities); proposed continuum of services; prevention; preschool education (early identification, content of educational intervention, range of programs); education of the school age child (physical settings, educational programs and philosophy, personnel, teacher preparation, costs, staff ratio considerations and characteristics, assessment and curricula planning resources, parent involvement and counseling); residential programs; and the autism service center concept. Additional chapters cover a sample budget for providing a psychoeducational program for five autistic children, a summary of the autism study findings, a summary of Title XX provisions, a chart with legislative information, a copy of the autism bill of rights, and a list of references. (SBH)

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The Illinois Autism Study

Illinois State Board of Education

Department of Specialized Educational Services

and

The Governor's Planning Council

on Developmental Disabilities

July, 1979

Don Muirheid, Chairman
State Board of Education
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BACKGROUND

In the Spring of 1978, the Governor's Planning Council on Developmental Disabilities and the Department of Specialized Educational Services of the Illinois Office of Education, agreed that they would jointly sponsor an autism study. Content of the study would include a review of relevant legislation, on site visits to a limited number of programs, information about prevalence rates, description of the existing system, identification of service deficits and gaps, development of a model comprehensive continuum of services from conception through adulthood, and a statement of actions necessary to implement the model. The proposed system would reflect the philosophy of the Autism Bill of Rights (see appendix).

An Autism Advisory Council was formed representing parents, private and public providers of services, geographic diversity, and persons knowledgeable in the field. The function of the council was to provide expert input from varying perspectives, to recommend courses of action, and to review materials developed in the course of study.

The Autism Advisory Council adopted, for the purpose of this study, the following definition of autism:

> **AUTISM IS A DEVELOPMENTAL DISABILITY WHICH IS MANIFESTED BY A COMBINATION OF SIGNIFICANT DISTURBANCES IN INTELLECTUAL, SENSORY, COGNITIVE, SOCIAL, PHYSIOLOGICAL, AND EMOTIONAL FUNCTIONING AND IS DISTINGUISHED FROM OTHER RELATED DISORDERS BY: IMPAIRED OR DISORDERED LANGUAGE AND COMMUNICATION; FAILURE TO DEVELOP APPROPRIATE SOCIAL RELATIONSHIPS; RITUALISTIC OR COMPULSIVE BEHAVIORS.**

The time frame of the study was one year. This limitation dictated methodology and procedure. For example, methodology utilized was informal polling rather than formal and statistically valid inquiry. Procedure was restricted to limited numbers of site visits. Although urban, rural, public and private programs were included, they were not necessarily representative of the total diversity of programs in operation throughout the state.

The final product, delineation of a model system of services, reflects some of the conclusions reached during the course of the study:

1. **There is no ideal system.** Although the proposed system seeks to ensure basic rights and minimal levels of services for all autistic children and their families, the pursuit of an ideal system is at the very least an unproductive use of time and energy. A realistic expectation is that given the current state of knowledge about autism and the identified needs of autistic persons and their families, a dynamic and evolving system may be implemented.

2. **The system must be flexible.** First of all, autistic individuals and their families share only one commonality: the experience of autism. Family composition varies; family resources vary; the severity of the affliction varies. To chart a monolithic system is not only unrealistic but counter-productive to the welfare of autistic persons and their families.

   An equally important consideration is the diversity of communities in which autistic persons reside. Treffert's study of 1971 confirms that distribution of the autistic population correlates positively with socio-demographic features of the general population. Autism occurs in rural and urban areas in expected ratios. Education and income level of parents of autistic children are not significantly different from those of the general population.

   A further consideration is that the extremes of Illinois represented by Chicago Metropolitan Area in the north and rural Illinois in the south require system flexibility to accommodate a broad diversity of community characteristics, resources and needs.

An additional factor impinging on the proposed system is the vigor with which families and professionals support the proposed system changes. To identify service deficits and gaps and to propose actions necessary to address these deficiencies is futile unless there is concomitant commitment to translate paper proposals into accomplishments.

A further factor affecting the completed study was the recognition that, within this time frame, not all issues could be addressed in sufficient depth. As basic services affecting all of the population at some point in their lives, the educational and residential components were determined to be priority issues. Therefore, these subject areas constitute a major part of the report.

Throughout the course of the study, parents and professionals were asked about what problems they were experiencing and what services they recognized as desirable and necessary. The following lists were developed, not in order of priority or frequency, but to identify the concerns expressed by individuals and by organizations. Although the completed study does not sequentially address the identified issues, each one is accommodated within the report.

SERVICE DEFICITS AND GAPS IDENTIFIED BY PARENTS AND PROFESSIONALS

I. Service Issues

A. Prevention

1. Information dissemination
2. Support of critical interventions and intervenors

B. Early Identification

1. Skilled diagnosticians
2. Appropriate resources
3. Information and referral
4. Follow-up

C. Individualized Educational Programs

1. Communications development and remediation
2. Social skill development
3. Physical skill development
4. Self skill training
5. Academic sequence

D. Family Support Services

1. Information and referral
2. Trained babysitters
3. Trained homemakers
4. Respite care, in and out of home
5. Crisis resources
6. Extended day care for working parents
7. Family services
8. Worker/advocate
9. Family counseling
10. Parent management-training
11. Financial assistance
12. Legal counsel

E. Medical Care

1. Medical diagnosis
2. Medical remediation
3. Medical maintenance
4. Nutrition, dietary assessment and counseling

F. Employment-Related Services

1. Vocational assessment
2. Pre-vocational training
3. Vocational training
4. Sheltered employment
5. Supervised employment
6. Regular employment

G. Residential Options

1. Foster care
2. Small group homes
3. Semi-independent living
4. Independent living

H. Community Activities

1. Recreation and leisure activities for autistic individuals
2. Social interaction with non-autistic persons
3. Family recreation programs/activities
4. Community integration: family and child

I. Transportation

J. Other

1. Toys and play materials
2. Curriculum materials

II. System Issues

A. Administration/Management

1. Funding
2. Interagency coordination
3. Interagency communication and cooperation
4. Service deficits and gaps
5. Data retrieval mechanisms
6. Evaluative procedures

B. Legislation, Policy, Rules and Regulations

1. Modification of
2. Initiation of

C. Philosophical/Intervention Questions
   1. Least restrictive environment
   2. Least restrictive methodology
   3. System flexibility

D. Staff Education/Training
   1. Teachers
   2. Related personnel
   3. Teacher aides
   4. Babysitters
   5. Homemakers
   6. Continued education
   7. In-service training

E. Other Issues
   1. Twelve-month programming
   2. Staff competency
   3. Monitoring: programs and personnel

DESCRIPTION OF THE POPULATION

> Each autistic child is an individual, and is different in many ways from other children with the same diagnosis. This is partly because the condition may be present in any degree varying from very mild to very severe, but also because each child has his own personality which somehow comes through despite his handicaps (Wing, L., 1972).

I. **Historical Overview.** During the last three decades, the syndrome identified as autism has gained increasing recognition as a unique disability. A brief account of the historical background preceding the more recent developments follows: In 1799, a French physician, J.M.G. Itard, was put in charge of a twelve-year-old boy, Victor, subsequently referred to as the "Wild Boy of Aveyron." The initial impression of Itard was that the peculiar behaviors of the child were the result of his having been deprived of human contact from an early age. It seems more likely now that the boy's intractable behaviors had caused his abandonment rather than that his behaviors were the result of environmental influences.

Itard was challenged by the boy, whom he saw as a natural savage, and set about the task of designing an education for him. Both his description of Victor and the methodology he developed to educate the child are amazingly relevant to current clinical descriptions of autistic children and to current effective remediation techniques.

The first impression of Victor as written by Itard describes a dirty, unkempt child with spasmodic movements, showing no affection for anyone, not focusing on any person or object, failing to show any reaction to a pistol shot behind his head, but alert to the sound of a walnut being opened, no matter how quietly (Wing, 1976). He resisted any change in his environment and had an uncanny memory for the precise order of objects, an order he was devoted to maintaining. He displayed exceptional drive and persistence in getting something that he wanted. He liked to feel things and showed a preference for touching and smelling and limited use of hearing and seeing.

Itard exploited the characteristics unique to Victor as a means to advancing his education and social development. Thus, Victor's fondness for certain foods, his rote memory, and his obsessive characteristics were put to use in Itard's program to civilize and humanize his charge.

Although Victor never became "normal" and never spoke, he did learn to read some words and to communicate nonverbally. His social behavior showed dramatic improve-

ment. Madame Guerin who "with all the patience of a mother and the intelligence of an enlightened teacher" took care of Victor was probably equally important to his remarkable progress (Wing, 1976).

Itard eventually recognized that he was mistaken in his supposition that Victor was normal, but uneducated. Pinel, another distinguished physician of that same period, had theorized all along that Victor was an idiot and incapable of learning. Itard, faced with the limits of what his and Madame Guerin's ministrations could achieve, judged his efforts a failure.

Probably because neither Itard nor his peers realized the implications of what he had accomplished, more than a century passed before a similar effort was made. It is interesting, however, that Itard's methods of remedial education were later taught to Seguin who in turn influenced Montessori. Thus, his perceptive observations and techniques do survive into the present.

More than a century later, early in the 20th century, an American psychologist, Lightner Witmer, described his technique for educating a young child who would now be diagnosed as autistic. At the age of thirty months, the child spent most of his time looking at and scratching the surface of a card. His parents evoked no affectional response in him; attempts to remove the card from him, however, resulted in violent tantrums. Witmer observed the concentrated attention the child gave to the few objects that interested him and judged that this characteristic indicated intellectual potential. He learned that this same characteristic of perseveration was also a major block to any kind of learning since the vehemence of his resistance to change immobilized efforts to introduce new learning.

With the help of a firm but gentle teacher, the child did make remarkable progress. He never became totally "normal" in his reactions to certain ordinary objects, remaining fearful of some and excessively attached to others. His speech developed but showed some robot-like qualities. However, the transformation from a child who was originally evaluated as hopelessly subnormal to a verbal human being with some peculiarities was a landmark achievement.

Witmer stated:

> "The first task of parent and teacher is to gain and hold the child's attention by giving him something he can do and, after that, something he can't do. . .I watch the child to discover what he can do with interest and ease and from here I get him to take a step forward in the direction best calculated to bring him to the next highest level of attention." (Wing, J, 1976).

Witmer's observations were both original and sound. More than fifty years later, precepts of educational strategy stress that, first of all, one must get the attention of the child and that progress depends on accurate perception of the individual's successes as well as failures.

Just as the significance of Itard's contribution was not recognized, the implications of Witmer's work failed to be noted. That there was a distinct group of children who evidenced cognitive problems different from those of the globally retarded was not recognized until 1943 when Kanner described eleven children whose behavioral features seemed to him both unusual and characteristic. In 1978, Rutter would designate these behaviors as specific (not usually present in most other populations) and general (almost always present in the autistic population).

Kanner's clinical brilliance is attested to by the researchers of the intervening years who have been and are involved in the study of autism. He abstracted as diagnostic criteria failure as an infant to assume an anticipatory posture preparatory to being picked up, failure to develop meaningful communication,* good rote memory, delayed echolalia, inability to grasp abstractions, insistence on sameness, lack of normal affectional response, inability to engage in imaginative play, and a general appearance of alertness and physical well being.

Classical, early infantile autism is the term most generally used now to identify those children who meet the criteria described by Kanner. Subsequent studies suggest that just as no single individual may exhibit all the symptomatology of a familiar physical disease, so no one individual is likely to evidence all the symptoms characteristic of autism. Reluctance to diagnose and treat a manifested physical disease with some a-typical features, however, could in some instances be fatal.

Current professional efforts to refine the definition of autism recognize the necessity to develop greater diagnostic precision. Concomitantly there is recognition that preoccupation with minute diagnostic discrepancies can impede progress. Further, for the current generation of autistic children, delay in instituting known methods of intervention may mean consigning them to the role of vegetating organism, denying them the opportunity to grow and develop within whatever limitations the handicap may impose.

*There are verified reports of autistic children who developed and subsequently lost verbal skills between the ages of two and three. However, current evaluation is that these earlier verbal skills were developmentally deficient and incongruent with the child's chronological age.

II. **Current Theory: Diagnosis and Etiology.** Published information about autism takes various forms, among them: personal narrative, research studies, proceedings from symposia, recommendations for educational strategies, theories of etiology and treatment methods, compilations of articles about any of the above, and newsletters sharing techniques and observations.

The personal narratives authored by parents are written honestly and directly, immediately engage the reader's emotions, and at the same time describe behaviors characteristic of the population.

The only journal specific to autism is **The Journal of Autism and Childhood Schizophrenia** (now **The Journal of Autism and Developmental Disorders**) edited by Schopler and Rutter and published by Plenum Press, bi-monthly, since 1971. However, publications in the field of medicine (especially psychiatry), psychology, mental retardation, speech and hearing, and child development intermittently publish articles about some facet of the disability. Two other sources include some information about autism: state plans developed by Developmental Disabilities Councils and unpublished documents emanating from university-based research or grant-supported studies.

An article by Schopler (1978) defines one of the problems in diagnosis as published studies which (1) shifted from Kanner's original studies as regards the features of autism emphasized, and (2) included characteristics different from those described in the original Kanner publications. Inexperience and lack of intellectual or scholarly rigor are Schopler's explanation for the aforementioned spurious research which has confused and impeded progress in the field.

He hypothesizes that the very complexity of the syndrome increases the problem of diagnostic reliability. The diverse characteristics which are not totally present in every autistic child and the necessity for thorough biological and medical evaluations to eliminate identifiable physiological abnormalities further compound the problem of diagnosis. Assessment of environmental and familial factors must also be included in order to certify that these are not the causative factors.

Schopler further states that no developmental disorder has complete diagnostic precision, nor will autism. However, from a statistical perspective, autism poses particular problems because the more complex the parts, the fewer will be the number of children fulfilling all criteria. But, in order to accomplish reliable and valid research, there must be a clearly and consistently defined population.

The National Society for Autistic Children describes autism as "a rare condition

characterized by severe problems in communication and behavior and an inability to relate to people in a normal manner."

The Society describes as additional characteristics:

Healthy, intelligent and attractive in appearance.

Withdrawn, apathetic and unresponsive.

Resistant to change.

Disinterested in people and surroundings.

Unusually interested in inaminate objects.

Hyperactive.

Speech difficulties.

Sleeping difficulties.

The Society lists as early symptoms (birth to eighteen months)

Feeding problems, such as poor sucking.

Apathetic and unresponsive—showing no desire to be held or cuddled.

Constant crying, or an unusual absence of crying.

Disinterest in people and surroundings.

Unusual fear of strangers.

Repetitive movements, such as hand flapping, prolonged rocking and spinning, and head banging.

Obsessive interest in certain toys or mechanical appliances.

Insistence on being left alone and that the physical environment remain unchanged.

Ritvo (1976) separates the behavioral symptoms of autism into five areas (1) disturbances of perception, (2) disturbances of developmental rate, (3) disturbances of relating, (4) disturbances of speech and language, and (5) disturbances of motility.

Rutter (1978) lists four characteristics, validated by research studies, as almost always occurring in the autistic population and rarely occurring in children suffering from other disorders:

(1) A profound and general failure to develop social relationships

(2) Language retardation with impaired comprehension

(3) Ritualistic or compulsive phenomena

(4) Onset prior to 30 months

Rutter also states that there is generally a bi-polar distribution of childhood psychosis, i.e., (1) prior to age 3, and (2) in early adolescence. However, at about age 3, what he calls the degenerative psychoses may manifest themselves so that an earlier cut-off age

for autism may be diagnostically advantageous. Because of obvious difficulties in obtaining irrefutable data, Rutter's present recommendation is to accept the World Health Organization's definition of autism which uses 30 months as the cut-off date for onset of autism.

The causes of autism remain obscure. Among the hypotheses are the following:

1. Autism results from a defect in the homeostatic regulation of sensory input and motor output.
2. Autism results from a defect in cross-modal associations.
3. Autism results from a central cognitive defect as indicated by the autistic child's inability to decode language. (Ritvo, 1976)

Clinical researchers at Yale are focusing on analysis of dopamine, neopenephrine, and serotonin levels of autistic children and studying the correlation of laboratory findings with observable behavior. According to Dr. Donald Cohen, psychiatrist and associate director of the Children's Clinical Research Center of Yale University School of Medicine, autism is a pervasive developmental disturbance. "We feel that certain neuropsychiatric disorders are inborn — that they are disorders to which children's central nervous systems are tuned incorrectly at the very beginning of life. The problem of the autistic child is both neurological and psychiatric, and there is no point in making any distinction." (Dr. Donald Cohen as quoted in **Research Resources Reporter,** November, 1978, Vol. II No. 11 p. 4).

Most autistic children have no abornmal neurological findings early in life. Yet a large proportion evidence neurological disorders as they proceed into the adolescent years. These findings coupled with the assumption that current diagnostic instruments are inadequate and that early soft signs are overlooked, mean that the presence or absence of neurological disorder cannot be included or discarded as a diagnostic determinant.

Some theorists view autism as a neurotic reaction. However, non-autistic children who are reared in a non-institutional environment and who are provided even minimal amounts of nurturing develop affectional bonds and exhibit imitative behavior. The young autistic child, however, is more typically bland and non-discriminatory in his response to significant persons and may, at one end of the continuum, actively resist being touched or held or comforted. Parents describe both passivity and unrelenting screaming as typical of the infant. Patterning behavior is typically deficient.

Children who are victims of maternal deprivation may exhibit symptoms typical of autism. However, when the environment is remediated and the child receives adequate nurturing, he responds with affection and frequently catches up to his expected develop-

mental level. In contrast, there is no evidence that environment per se is responsible for autism. Although maturation is a significant factor in diminishing autistic behavior, the social behavior of even the higher functioning autistic adult retains a robot-like quality. Conversation tends to lack ease and spontaneity and there is continued insensitivity to emotional shading as well as inability to empathize.

Approximately 70% of autistic children are functionally mentally retarded; however, mentally retarded non-autistic children usually show a consistent pattern of retardation whereas autistic children are distinguished by the discrepancy between their developmental milestones. For example, some autistic children manifest splinter skills such as unusual musical ability. Also, the majority of mentally retarded children do not display the behaviors characteristic of autistic children. The differences are particularly evident between higher functioning autistic children and mentally retarded children.

The speech of schizophrenic and autistic children may be equally and similarly bizarre. However, schizophrenic children may experience periods of remission; autism on the other hand is a chronic disease. Hallucinatory material characteristic of schizophrenic children is absent in the production of autistic children. Autistic children usually lack the ability to imagine and fantasize and therefore the ability to hallucinate. A genetic-familiar factor is frequently present in the schizophrenic child's background. The families and ancestors of autistic children, on the other hand, do not exhibit the disability, although there is some evidence of speech peculiarities in the relatives of some autistic children.

Congenitally aphasic children share with many autistic children a failure to develop speech. However, this is an encapsulated disability of the aphasic child who otherwise shows normal affectional responses and develops some method of communication. The autistic child is also deficient in meaningful mime or gesture and tends to not develop alternatives to verbal communication.

The deaf child and the visually impaired child may display some autistic characteristics including motility aberrations. Remediation of the primary deficit of the deaf child results in behavioral changes whereas children who are diagnosed as both autistic and hearing impaired continue to manifest the same idiosyncracies when the hearing problem is remediated. Visually impaired children may exhibit "blindisms" such as hand flapping, but not the socially deficient behavior of autistic children. The exception to this is retrolental fibroplasia whose symptoms closely parallel those of autism.

III. **Illinois' Population.** Intrinsic to the problem of identifying the autistic population in Illinois are:

1) The lack of public and professional awareness of the characteristics of the syndrome
2) Diagnostic decisions based on administrative/funding policies
3) Exclusion of the disability from computerized data retrieval systems

Autistic children have traditionally been served in settings for the mentally ill and mentally retarded. This pattern still prevails especially as regards residential care. Both residential and non-residential programs (primarly provided by the Department of Mental Health/Developmental Disabilities and by the public education system) lack consistent reporting categories by which the population can be identified.

The Department of Mental Health and Developmental Disabilities provides services on both an outpatient and inpatient basis to individuals who are diagnosed as mentally ill or developmentally disabled. The autistic person is served under both umbrellas, depending in part on where he surfaced or connected to the system; on the degree of diagnostic expertise available at the critical time; and on the philosophical bias of the agency providing the service.

Because the greater proportion of autistic individuals function on a mentally retarded level, physicians or other significant referral sources frequently refer autistic children to programs for the mentally retarded. In other instances, the referral is directly to an agency funded for services to the mentally ill. Sometimes the autistic child is in turn referred by one agency to the other.

Funding availability also affects diagnosis. Children who need to be placed in residential treatment settings, may be rediagnosed when they leave the community. If there is money in the developmental disabilities system, it is advantageous to categorize the child as mentally retarded. On the other hand, if a diagnosis of mental illness can qualify the individual for residential placement, this may be the diagnosis used. Tracking the autistic individual through the system becomes virtually impossible. Obviously, diagnoses used for administrative purposes are both useless and deceptive. Only by reviewing in detail thousands of case records would it be possible to find out where autistic persons actually are.

A further difficulty in identifying the population results from administrative funding requirements. As major receivers and dispensers of tax funds, the federal, state and local education agencies are locked into numerous accountability systems. In the area of special education, accountability requirements seemingly proliferate in proportion to the

number of special services provided handicapped children.

Among the elements of accountability are reports generated at each governmental level specifying how many of what kinds of children are receiving specialized educational services.

The intent is not only to be sure that each child needing specialized educational services receives them, but conversely to make sure that students are not inappropriately identified as in need of these services. One way of documenting that a child has needs for services beyond those provided in a regular classroom is to name the particular disability which interferes with his ability to benefit from regularly provided instruction. Thus, classifying children into diagnostic categories is the customary mechanism for providing the information which is an essential element of accountability systems. The allocation of funds and the resultant provision of necessary services are then, in large part, dependent on counts by diagnostic category.

Expensive and time consuming as accountability systems are, they have the potential for being even more costly and unruly. One method of cost containment is limiting the number of reportable diagnostic categories. If reporting systems were refined to accommodate every known disability, costs would increase at every level and an increasing amount of money would be diverted from providing direct service.

Categories of children reported by local educational agencies to state education agencies correspond to those listed in relevant Federal rules and regulations. For purposes of 94-142 legislation, the term **handicapped children** means the mentally retarded, hard of hearing, deaf, orthopedically impaired, other health impaired, deaf/blind, multihandicapped, seriously emotionally disturbed, speech impaired, learning disabled, and visually handicapped. Autism is one of the disabilities that is not specifically reported under P.L. 94-142 regulations. Therefore, as local educational agencies report to state agencies how many children in what diagnostic categories are being served, autism is not included. Instead, Federal Rules and Regulations implementing P.L. 94-142 state that autistic children are to be reported in the "seriously emotionally disturbed category." The categorical counting of children in order to comply with legislative requirements and thus to qualify for financial support is then among the reasons that the autistic population is not a visible statistic in the education system.

IV. **Prevalence Rates:** Because of these difficulties, the most practical means of determining how many autistic persons there are in Illinois is to use well documented prevalence studies. Among the most eminent and respected researchers in the field of autism and

related conditions is Lorna Wing, M.D., Member of the Scientific Staff, Medical Research Council, Institute of Psychiatry in London. Her prevalence studies are carefully designed and the data derived therefrom has been substantiated in subsequent studies.

Dr. Wing in her second edition of **Early Childhood Autism** (1975) reviews the epidemiological studies of Lotter, Brask, and Treffert. Each researcher reported prevalency rates as determined by the results of his studies.

In 1964, Lotter utilized the total population of 78,000 children aged 8, 9 or 10 in the former county of Middlesex. From the first screening, 135 cases of possible early infantile autism were identified for a prevalence rate of 4.5 per 10,000. In 1979, Brask undertook a survey in Denmark using a population of children between the ages of 2 and 14 and derived similar ratios. In 1970, in Wisconsin, Treffert examined cases of all children seen for evaluation in residential and outpatient facilities or in special schools for whom a diagnosis of childhood schizophrenia was made and identified a subset of children who met the criteria of classical infantile autism. The results of these epidemiologial surveys do not lend themselves to comparative analysis because the populations differed, the screening instruments differed, and the diagnostic criteria differed.

More recently Wing has completed a study yielding a 20.1 per 10,000 rate which seems to have empirical value in assessing how many children share autistic characteristics which would require similar kinds of therapeutic interventions. The population studied included all children under age 15 whose parents lived in the former borough of Camberwell who had come to the attention of medical, social, or educational services because of developmental or behavioral aberrancies. From this population, Dr. Wing then screened on the basis of one or both of two criteria:

Criterion I

a) Absence or impairment of social interaction, especially with peers
b) Absence or impaired development of verbal and non-verbal language
c) Repetitive, stereotyped activities of any kind

Criterion II

a) Level of function on formal tests in the severely retarded range
b) Level of function in education achievement in the severely retarded range

As a result of extensive interviewing of teachers and parents and of observation and testing of the 132 children thus identified, a population of 74 was factored which evidenced

the following unique characteristics unrelated to IQ or the presence of secondary handicaps:

1. Absence of two way social interaction.
2. Problems with language and communication, both verbal and nonverbal.
3. Absence or severe impairment of any kind of imaginative play. (What might at first observation appear to be imaginative play in a small number of children was in fact repetition of phrases or activities, sometimes echoing of TV phrases, that could not be modified, i.e., socially influenced, by other people).

The criteria used were broader than those used in Lotter's study which yielded a prevalence rate of 4.5 per 10,000. One of the observations made of autism and of any other disability is that the narrower the definition, the smaller the population falling within the criteria. The implications of adhering to limited and rigid criteria are that (1) many children who may benefit from a set of interventions are excluded and (2) it becomes economically and administratively unfeasible to address the needs of multiple and separate populations.

Dr. Wing's study disregarded diagnostic labels already attached to the children who were subjects of this study. Methodology, including correlations of rater reliability and refinement of the global criteria, is carefully explicated in the published report (Wing, 1979). The results of her study, a prevalancy rate of 20.1 per 10,000 when severity of social impairment (independent of degree of mental retardation or previous diagnosis of autism) is measured has implications for both further research and for current planning. In education, a severe social impairment affects the way learning takes place. In life time planning, severe social impairments affect the eventual goals of independent living and vocational performance.

Planning for the autistic population requires information that is both quantitative and qualitative. In Illinois, information in either domain is lacking.

Some states gather quantitative data by listing autism as a separate disability in their school codes. New York has also specified qualifications for teachers of autistic students. Michigan has adopted a policy statement relative to class size and educational methodology.

An example of statutory inclusion is California's definition of autism (**California Administration Code,** Article III, Section 3230):

(1) The behavioral manifestations are so severe a pupil cannot fully benefit from regular educational classroom attendance, although the pupil may display

evidence of cognitive potentialities. A pupil will exhibit some combination of the following characteristics:

(A) Unable to use oral language for appropriate communication.

(B) A history of not relating to people appropriately and continued impairment in social interaction from infancy to early childhood.

(C) An obsession to maintain sameness.

(D) Preoccupation with objects and/or inappropriate use of objects.

(E) Extreme resistance to controls.

(F) Displays peculiar motoric mannerisms and motility patterns.

(2) The behavioral manifestations are of such severity that the pupil's level of functioning requires uniquely different educational interventions over a prolonged period of time.

(3) The disorder shall be determined by a medical evaluation or through a psychological evaluation by a credentialed or licensed psychologist as part of the psycho-educational study and health study pursuant to Section 3231 (a) and (f) of this Title.

In establishing prevalency rates for Illinois population, the school age population (6-18) of 1970 was used as the basis for the following tables. A 4.5 per 10,000 prevalency rate using Lotter's study based on the characteristics of early infantile autism was applied to county and regional school age populations. In the light of Dr. Wing's more recent study, a 20 per 10,000 rate was also applied because of its probable significance to planning a comprehensive continuum of services.

AUTISM POPULATION ESTIMATES: STATE OF ILLINOIS

County	Educational Service Region	Elementary School Enrollment 1977 (Ages 6 up)	Secondary School Enrollment 1977	Total County Enrollment (School Age)	Total Region Enrollment (School Age)	Projected #Autistic children in Region (4.5 per 10,000)	Projected #Autistic like children (20 per 10,000)[1]	#Teachers needed (1:5 ratio)[2]	Projected #Total Population Autistic in county (4.5 per 10,000)
Adams	01	8,494	4,319	12,813	12,813	5.76	25.62	5.1	31.88
Alexander	02	1,506	759	2,265					5.4
Pulaski	02	1,407	781	2,188	4,453	2.00	8.90	1.78	3.93
Bond	03	1,834	963	2,797					6.3
Fayette	03	2,692	1,352	4,044	6,841	3.08	13.68	2.73	9.33
Boone	04	4,537	2,122	6,659					11.43
Winnebago	04	35,382	16,559	51,941	58,600	26.3	119.2	23.8	110.98
Brown	05	699	405	1,104					2.51
Cass	05	1,996	1.048	3.044					6.39
Schuyler	05	1,015	511	1,526	5,674	2.55	11.34	2.26	3.66
Bureau	06	5,548	2,761	8,309	8,309	3.74	16.61	3.32	17.34
Calhoun	07	516	429	945					2.55
Jersey	07	2,324	1,335	3,659	4,604	2.07	9.20	1.84	8.32
Carroll	08	3,039	1,396	4,435	4,435	2.00	8.87	1.77	8.67
Champaign	09	18,030	8,729	26,759	26,759	12.04	53.51	10.7	73.476
Christian	10	5,286	2,909	8,195	8,195	3.69	16.38	3.27	16.176
Clark	11	2,430	1,206	3,636					7.29
Coles	11	5,604	2,865	8,469					21.51
Cumberland	11	1,536	786	2,322					4.39
Moultrie	11	1,518	768	2,286	16,713	7.52	33.42	6.68	5.96
Clay	12	2,210	1,108	3,318					6.63
Jasper	12	1,407	872	2,279	9,136	4.11	18.27	3.65	4.83
Richland	12	2,236	1,303	3,539					7.57
Clinton	13	4,276	1,636	5,912	8,317	4.19	16.63	3.32	12.74
Washington	13	1,499	906	2,405					6.2
Cook	14	623,242	305,071	928,313	928,313	417.74	1856.26	371.23	2469.53
Crawford	15	2,956	1,445	4,401	4,401	1.98	8.80	1.96	8.92
DeKalb	16	9,372	4.778	14,150	14,150	6.37	28.32	5.66	32.24
DeWitt	17	2,477	1,232	3,709	3,709	1.67	7.41	1.49	7.63
Douglas	18	2,829	1,360	4,189	8,586	3.86	17.17	3.43	8.54
Piatt	18	2,865	1,532	4,397					6.97

1. See Wing Study of 1979
2. Article IV 4.04.2 Rules and Regulations to Govern the Administration and Operation of Special Education (Program size limit of five for severe, multiply impaired children)

County	Educational Service Region	Elementary School Enrollment 1977 (Ages 6 up)	Secondary School Enrollment 1977	Total County Enrollment (School Age)	Total Region Enrollment (School Age)	Projected #Autistic children in Region (4.5 per 10,000)	Projected #Autistic like children (20 per 10,000)[1]	#Teachers needed (1:5 ratio)[2]	Projected #Total Population Autistic in county (4.5 per 10,000)
DuPage	19	83,251	43,812	127,063	127,063	57.18	254.12	50.82	221.34
Edgar	20	2,879	1,431	4,310	4,310	1.94	8.62	1.92	9.71
Edwards	21	904	420	1,324					3.19
Wabash	21	1,787	866	2,653	3,977	1.79	7.85	1.57	5.77
Effingham	22	3,966	2,084	6,050	6,050	2.72	12.1	2.4	11.07
Ford	23	2,127	1,150	3,277	5,277	2.37	6.55	1.31	7.37
Franklin	24	5,820	2,571	8,391	8,391	3.78	16.78	3.35	17.248
Fulton	25	7,208	3,452	10,660	10,660	4.80	21.32	4.26	18.85
Gallatin	26	1,006	506	1,512					3.33
Hardin	26	771	337	1,108					2.21
Pope	26	587	284	871					1.73
Saline	26	3,759	1,686	5,445	8,936	4.02	17.87	3.57	11.57
Greene	27	2,185	1,210	3,395	3,395	1.53	6.79	1.35	7.65
Grundy	28	4,872	2,653	7,525	7,525	3.39	15.05	3.01	11.94
Hamilton	29	1,047	559	1,606					3.89
Jefferson	29	5,155	2,249	7,404	9,010	4.05	18.02	3.60	14.15
Hancock	30	3,517	1,826	5,343	5,343	2.40	10.68	2.13	10.64
Henderson	31	1,053	575	1,628					3.8
Warren	31	3,074	1,539	4,613	6,241	2.81	12.48	2.49	9.71
Henry	32	8,886	4,106	12,992					23.94
Stark	32	1,184	659	1,843	14,835	6.68	29.67	5.93	3.37
Iroquois	33	4,746	2,548	7,294	7,294	3.28	14.58	2.91	15.08
Jackson	34	6,430	3,164	9,594	9,594	4.32	19.18	3.83	24.75
Jo Daviess	35	3,186	1,788	4,974	4,974	2.24	9.92	1.98	9.79
Johnson	36	1,250	667	1,917					3.39
Massac	36	1,957	974	2,931	4,848	2.18	9.69	1.93	6.25
Kane	37	50,588	22,375	72,963	72,963	32.83	145.92	29.18	112.95
Kankakee	38	14,244	6,732	20,976	20,976	9.44	41.85	8.37	112.95
Knox	40	7,865	4,078	11,943	11,943	5.37	23.88	4.77	27.81
Lake	41	63,250	31,774	95,024	95,024	42.76	190.048	38.00	172.18
LaSalle	42	13,331	7,675	21,006	21,006	9.45	42.01	8.40	50.13
Lawrence	43	2,434	1,221	3,655	3,655	1.64	6.310	1.46	7.88
Lee	44	4,770	2,433	7,203	7,203	3.24	14.406	2.88	17.07

1. See Wing Study of 1979
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Livingston	45	5,487	3,105	8,592	8,592	3.97	16.18	3.23	18.31
Logan	46	3,109	1,923	5,032					15.09
Menard	46	1,918	939	2,857	7,889	3.55	14.77	2.95	4.35
Macon	47	18,116	8,726	26,842	26,842	12.08	53.68	10.73	56.25
Macoupin	48	7,382	3,797	11,179	11,179	5.03	22.35	4.47	20.04
Madison	49	34,342	18,453	52,795	52,795	23.76	105.49	21.09	112.92
Marion	50	5,931	3,414	345	9,345	4.21	18.69	3.73	17.54
Marshall	51	2,029	1,090	3,119					5.98
Putnam	51	947	377	1,324	4,443	2.00	8.88	1.99	2.25
Mason	52	3,456	1,460	4,916	4,916	2.21	9.83	1.96	7.27
McDonough	53	3,957	2,012	5,969	5,969	2.69	11.93	2.38	16.49
McHenry	54	19,340	9,486	28,826	28,826	12.97	57.65	11.53	50.19
McLean	55	14,274	6,772	21,046	21,046	9.47	42.09	8.41	46.97
Mercer	56	3,182	1,634	4,816	4,816	2.17	9.63	1.92	7.78
Monroe	57	2,276	1,325	3,601	3,601	1.62	7.20	1.45	8.47
Montgomery	58	4,197	2,213	6,410	6,410	2.88	12.82	2.56	13.61
Morgan	59	4,623	2,249	6,872					16.27
Scott	59	838	475	1,313	8,185	3.68	16.27	3.25	2.74
Ogle	60	7,456	3,784	11,240	11,240	5.06	22.48	4.49	19.29
Peoria	61	25,767	11,574	37,341	37,341	16.80	74.68	14.93	87.89
Perry	62	2,592	1,302	3,894	3,894	1.75	7.76	1.55	8.89
Pike	63	2,786	1,342	4,128	4,128	1.86	9.25	1.85	8.63
Randolph	64	3,767	2,149	5,916	5,916	2.66	11.83	2.36	14.12
Rock Island	65	21,043	10,602	31,645	31,645	14.24	63.28	12.65	75.03
St. Clair	66	38,581	18,350	56,931	56,931	25.62	113.86	22.77	128.32
Sangamon	67	19,525	9,906	29,431	29,431	13.24	58.86	11.77	72.6
Shelby	68	3,222	1,619	4,841	4,841	2.18	9.68	1.93	10.16
Stephenson	69	6,581	3,300	9,881	4.45	19.76	3.99	21.98	
Tazewell	70	18,750	9,353	28,103	28,103	12.65	56.20	11.24	53.39
Union	71	2,726	1,169	3,895	3,895	1.75	6.79	1.35	7.23
Vermillion	72	13,401	6,421	19,822	19,822	8.92	39.64	7.92	43.67
Wayne	73	2,369	1,178	3,574	3,574	1.60	7.09	1.41	7.65
White	74	2,549	1,316	3,865	3,865	1.74	7.73	1.54	7.79

1. See Wing Study of 1979
2. Article IV 4.04.2 Rules and Regulations to Govern the Administration and Operation of Special Education (Program size limit of five for severe, multiply impaired children)

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Whiteside	75	9.856	4.966	14,822	14,822	6.67	29.64	5.92	28.29
Will	76	46,278	19,963	66,241	66,241	29.81	132.48	26.49	112.274
Williamson	77	7,445	3,367	10,812	10,812	4.87	21.62	4.32	22.05
Woodford	78	5,047	2,605	7,652	7,652	3.44	15.30	3.06	12.6
DOC	80	827	2,976	3,803		1.71	7.6	1.52	
Total State		1,411,626	722,110	2,183,736		982.68	4367.47	873.49	4999.25*

*1970 census figures for population used throughout the total population column

1. See Wing Study of 1979
2. Article IV 4.04.2 Rules and Regulations to Govern the Administration and Operation of Special Education (Program size limit of five for severe, multiply impaired children)

V: PROBLEMS AND RECOMMENDATIONS

Problem: **Data Retrieval** There is no reliable information system which identifies autistic persons or programs for them in the State of Illinois.

Recommendations: (1) Local Education Agencies and local DMH/DD agencies should be provided criteria for the diagnosis of autism.

(2) The Illinois Office of Education reporting forms should include autism as a separate disability. (Number of autistic students may be added to numbers of emotionally disturbed students to arrive at the necessary Child Count for 94-142 reporting).

(3) Computer systems in the Illinois Office of Education and the Department of Mental Health/Developmental Disabilities should be programmed to capture the data.

Problem: **Legislative Discrepancies** Contradictions in federal and state legislation contribute to the confusion in the service delivery system.

(1) The Basic Developmental Disabilities Act, PL 94-103 defines autism as a developmental disability.

(2) The Education for all Handicapped Children Act (PL 94-142) places autism in the emotionally disturbed category.

(3) Illinois' Mental Health Code (Public Act 80-1414, Section 1-106) includes autism as a developmental disability.

(4) The School Code of Illinois does not identify autism as a separate disability.

Recommendations: (1) On the federal level, the National Association for Autistic Children should continue to work with the Bureau of Education for the Handicapped to redefine autism in the **Rules and Regulations to Govern the Implementation of P.L. 94-142.**

(2) Illinois' School Code should be amended to include and define the disability of autism.

(3) The Governor's Planning Council on Developmental Disabilities and the Autism Advisory Council should keep apprised of the current deliberations among state agencies relative to the definitions of educational/therapeutic services and of the assignment of financial responsibility for these services.

CURRENT SERVICE SYSTEM

> The complexity, lack of control, and disorganization of the system currently delivering services to handicapped youth defies efficient and effective operations; inequities and gaps in service delivery abound; and not enough information is available to manage the service system effectively and deliver the services needed. (Brewer and Kakalik, 1979, p.15)
>
> Partly because of the sheer number of institutions dispensing funds and services under many pieces of enabling legislation, no one person or group plans, monitors, or controls the handicapped service system in any comprehensive fashion. Policymaking, funding, and operating decisions are often made by entirely different groups of people, who have little or no data about program effectiveness to guide them; consequently accountability is generally very weak. (Brewer and Kakalik, pp. 17.18)

I. **Characteristics of the System:** The current system of services in Illinois is typical of a service system which

(1) Developed in response to local needs

(2) Originated in the volunteer sector

(3) Was developed subsequently by the public sector primarily in response to legislative action

(4) Omitted systematic planning processes.

There are both advantages and disadvantages integral to this not uncommon method of developing human services. An examination of each one of these factors in respect to advantages, disadvantages and current functioning will illuminate the present system of services to autistic persons in Illinois.

(1) **Development in Response to Local Needs**

Advantages: When a problem is recognized as affecting either in quantity or intensity a subset of the population and when a group of citizens joins together to provide answers to the problem, the solution tends to more precisely address the recognized need than a solution promulgated at a distant or administrative level. Also, the services developed are generally more immediately available. Unimpeded by the restrictions and rules and regulations inherent in state or federal beneficences, the local sponsors can respond more flexibly and, in at least this one aspect, more efficiently to identified local needs.

Disadvantages: Because the local citizens usually confine their efforts to addressing only a visible and acute problem, there is less likelihood that the total dimensions of the problem will be recognized or anticipated. For instance, services developed for a limited age group will be outgrown more rapidly than seemed likely and will no longer be relevant to the emerging age group. Further, efforts to maintain local services may encapsulate a program effort and limit its strength or necessary growth. In order to develop a constituency which will assure maintenance of the initial effort as well as to accrue the power essential to promoting future growth, service systems must extend beyond the local level.

(2) **Origins in the Voluntary Sector**

Advantages: When a community service originates in the volunteer sector, it benefits from a kind of energy which frequently exceeds that emanating from a typical paid staff. It is not only that the volunteer is not in thrall to a 9-5 day. The extra dimensions of enthusiasm, naivety, and belief in a cause serve as multipliers, accomplishing the improbable and even the impossible. Most respected and venerable human institutions are the result of citizen determination to alleviate a problem or to elevate humanity. Citizen determination is the progenitor of both public school education and the New York Philharmonic.

Disadvantages: At some point in time, in order to ensure that all persons needing or desirous of participating in a program do, in fact, have access to its benefits, formalizing the program becomes necessary. Organizational structure, financial support, and paid staff are inevitable accompaniments to stabilizing program services and extending them to the critical population. A handful of volunteers can successfully address only a limited number of issues. The initial wave of optimism is tempered by the inescapable realities or political, financial and personality difficulties. Solutions usually progress from (1) dependence on volunteer workers and voluntary contributions to (2) charging fees to recipients of services to (3) a growing demand for services and a commensurate increase in the numbers of program staff to (4) hiring administrative staff, and (5) to requiring public tax support. In the final organizational stage, the price of assuring both program continuity and program expansion is capitulation to the requirements of government bureaucracy.

(3) **Public and Legislatively Mandated Programs**

Advantages: The most immediate and visible advantages of public and legislatively mandated programs are a stable if minimal level of financial support and concomitant extension of program availability to all citizens. Tax-based support usually assures not only continuation of the original service but has the potential for initiating additional services to fulfill unmet needs. Public tax support also demands public accountability and mechanisms

ensue to guarantee that all citizens shall have access to programs necessary to their health or well-being rather than being dependent on the uncertain distribution of volunteer sponsored programs.

Disadvantages: When formerly voluntary programs move into the area of public support, an element of accountability is lost as well as gained. The expansion of programs and increased numbers of staff automatically make more difficult the problem of quality control. Program changes to accomodate changes in philosophy or research findings become more difficult to implement. In contrast to programs established because of the dedication or determination of a small group of volunteers, public programs may exist only to comply with legislative mandates and may be distinguished by dedication to form rather than substance. The level of tax appropriation may limit rather than expand program effectiveness and provide a thin system of services not fully meeting the needs of anyone.

(4) **Omission of Systematic Planning**

Advantages: An increasingly vocal minority believes that the recent and current infatuation with planning has all too frequently co-opted resources of time, people and money that could more fruitfully have been activated into providing services to persons in need. Months of planning effort may produce only reams of rhetoric. Examination of five year plans in both private industry and the public sector would tend to support this skepticism. Sophisticated planners as well as reliable and valid data are both in short supply. The state of the art reflects both these deficiencies.

Disadvantages: Unless some attention is paid to available information and unless some systematic method is employed to address critical problems, there is equal likelihood that resources will be dissipated in fruitless endeavors. Planning is a vehicle that can assess the total dimensions of a problem, rather than address a single aspect. It can clarify those financial, political, and system elements necessary to continue and improve on existing service elements.

II. **System Background:** In 1979, Illinois maintains a multiple and fragmented service system for autistic individuals. The single component most consistently available falls under the rubric of educational services.

In order to gain a better perspective of the current educational programs for autistic children in Illinois, a brief examination of significant changes of the last 25 years is helpful.

The history of educational programs for autistic children is rooted in the development of educational programs for the mentally retarded. In the early 1950's, parents of mentally retarded children began to organize locally to provide some variant of community day care. Generally,

these were parents who refused to accept the recommendation to institutionalize their children. The programs were housed in churches and in abandoned buildings; they were financed by bake sales and bridge parties and donations. They were staffed by volunteers, generally parents. Program philosophy was pragmatic.

Admission criteria included the child's exclusion from public school, geographic accessibility, parental determination and sometimes the ability of the parents to pay for service. The autistic child was an acceptable candidate for community day programs. Differential diagnosis was in its infancy and the autistic child usually scored appropriately low on the standard intelligence tests.

It was also true that Freudian psychoanalytic theory was dominant. The autistic behaviors which did not yield to strategies successful with the mentally retarded child were ascribed to familial pathology. Generally, enrollment in the day program was relatively brief and institutional placement was the eventual recourse. Professionals and parents believed that failure could have been avoided if only the parents had tried harder, cooperated more or straightened out their marriages.

From these early small beginnings evolved day programs for the mentally retarded throughout most of the state. In Illinois, by 1978, there were 108 local Associations for Retarded Citizens, most of them providing an educational program now supported by state and local taxes as well as by voluntary contributions. Several factors contributed to this growth:

(1) The momentum of the parents movement in itself generated support and extension of day programs across the country.

(2) Local groups began to organize into state organizations that exerted political pressure for tax support in the legislature and for voluntary support from local amalgamated fund drives.

(3) Burgeoning institutional costs invited comparisons between the costs of residential and community-based care. As the less costly of the two alternatives, community care received increased political and financial support.

(4) Prcgram successes invalidated previous caveats that developmentally disabled citizens could not function, much less thrive, in the community setting.

As parents gained confidence, they began to litigate against discriminatory treatment of their children. Among critical discrimination issues was denial of educational opportunity to a population of school age children. As a result of a landmark court decision, degree of educability was no longer valid cause for exclusion from the public school system; the larger issue was violation of constitutional rights in abrogating the mandate to provide equal opportunity to all citizens.

When the previously unquestioned right of a school system to provide public education to only a subset of the population was determined illegal, educational programs for the developmentally disabled proliferated.

In Illinois, the passage of HB 2671 in 1969 recognized the rights of handicapped children to a share of education tax dollars whether they were served in a public or private setting. Even as the numbers of private facilities increased, an ever growing number of public school systems also began to provide classrooms for the moderately retarded. In subsequent years, the larger school systems in particular accommodated within their own structure a more profoundly and severely handicapped population.

Within this same time frame, the numbers of children living outside institutions increased dramatically. As a consequence of the public schools' mandate and the movement toward deinstitutionalization, the private day programs which had initially served a population at the upper end of mental retardation, changed their focus and addressed the needs of other populations, namely:

(1) The mentally retarded individual below and above school age, and

(2) The low incidence, multiply and severely handicapped population of school age.

As a severely handicapped child, the autistic child continues in many communities to receive educational services in private programs for the mentally retarded. Several factors contribute to this: tradition; the lack of experienced diagnostic personnel; the continued denial of autism as a separate developmental disability; the still pervasive philosophical belief that autistic behaviors are of psychogenic origin; unacknowledged dependence on numbers of children served as a means to private facility survival; the lack of educational options.

In Illinois, as in all states, there exist not only multiple service systems, reflecting legislative mandates and the rules and regulations implementing these mandates, but system variables contingent upon geographic location, economic status, and policy interpretations. When major federal legislation affecting several service providers is enacted, this diversity begins to yield and the intra-state system begins to shift. The most immediate result is some erosion of unique and local arrangements as diminution of control is both prelude and accompaniment to reducing system discrepancies.

Passage of Public Law 94-142 is a classic example of the legislative-catalytic process. Evidence of the impact is that across the country enactment of PL 94-142 has resulted in substantial litigation, the resolution of which will engender further legislative changes. It has already provoked examination of certain system traditions and is forcing some system realignments. Some of these changes have affected and will increasingly affect services provided to autistic persons.

Two major state agencies, the Illinois Office of Education and the Department of Mental Health/Development Disabilities, are primarily involved in providing services to autistic persons. Both agencies are also affected by the enactment of PL 94-142.

III. **The Department of Mental Health/Developmental Disabilities:** The Department is mandated to deliver appropriate inpatient (residential) services to all persons admitted or committed to its institutions for the mentally ill, developmentally disabled and the alcoholic. It also provides on an outpatient (non-residential) basis, the opportunity for appropriate treatment and care to all persons in danger of being institutionalized. It "seeks to ensure that each person needing services receives appropriate treatment in the least restrictive setting possible. The objective of services is to help clients improve their level of functioning and social competence and, where possible, maintain residence in their communities" (Illinois Human Services Plan, 1978-80).

The Department of Mental Health/Developmental Disabilities discharges its responsibilities in part by operating a state institutional system and by making grants to community agencies which provide a variety of services on an outpatient basis to the mentally ill and developmentally disabled. Through its Individual Care Grant program, it also funds, on an individual basis, residential care for individuals who cannot be served appropriately in state operated facilities.

In the 1960's, the Department, in its role of providing residential care, established Zone Centers throughout the state in geographic locations which assured access to mental health services within ninety minutes travel of all state residents. The intent of the Zone Centers was to provide short, intensive treatment that would reduce the need for lengthy and multiple hospitalizations. The Children's Residential Units operated with this same goal but with a somewhat extended time frame. In the 1960's, Illinois began a process of de-institutionalization from all facilities which effected a resident population decrease from a high of 55,000 in mid 1960 to 10,800 in FY '79 -- 6,500 developmentally disabled persons and 4,300 mentally ill (IL. State Budget, FY '79).

In the 1970's, as part of the institutional changes, Illinois funded 18 Community Living Centers which were smaller, community-based alternatives to massive institutions. The Community Living Centers were authorized to provide from 50 to 100 beds and to prevent the predictable problems associated with massive numbers of handicapped persons congregated together.

State residential facilities now include traditional large institutions, Zone Centers, Community Living Centers, some limited number of group homes. None of these residential resources provides programs specific to the needs of autistic persons with the possible exception of one Region which reports residential services for three children and one adult diagnosed as autistic.

The DMH/DD community agency system provides emergency intervention, outpatient counselling, follow-up services for formerly institutionalized persons, day treatment programs, and sheltered workshop activities. In some instances, a community agency operates a Community Living Facility. The Department funds about 30 Day Care Programs which may include undiagnosed autistic children. Rimland School in the north and the Illinois Center for Autistic Children in southern Illinois, both receiving DMH/DD funds, are the two Day Care educational programs identified as focusing specifically on the needs of autistic children and adolescents.

IV. **The Public Education System:** More than a century ago, the state of Illinois assumed responsibility for the education of its children as evidenced by Illinois' 1870 Constitution which in Article VIII specifically addressed schools and education. In the new Constitution of the State of Illinois, adopted in 1970, Article X deals solely with schools and education. Section I of the Article states:

> A fundamental goal of the People of the State of Illinois is the educational development of all persons to the limits of their capacities.
>
> The State shall provide for an efficient system of high quality educational institutions and services. Education in public schools through the secondary level shall be free. There may be such other free education as the General Assembly provides by law.
>
> The State has the primary responsibility for financing the system of public education.

As regards its actions, the legislature operates with only two restrictions: (1) it must do everything required of it by the Constitution and (2) it may not do anything forbidden it by the Constitution. In all other respects, it determines itself what actions it shall take. (Garber and Hubbard, 1975)

Among the legislative actions are the numerous laws relative to education enacted by the General Assembly. Chapter 122 of the **Illinois Revised Statutes** encompasses the Articles and a number of related acts which together comprise **The School Code of Illinois.** Although the General Assembly because of its legislative actions largely determines state educational policy, other key factors are the State Board of Education and the Superintendent of Education, who, as the chief school administrator for the State of Illinois, is assigned many duties by the Board and by statute.

In turn, the Superintendent of Education delegates many duties to the professional staff which comprises the Illinois Office of Education. The Department of Specialized Educational

Services as a component of that office is responsible for the education of children requiring specialized educational services. Pursuant to this responsibility, that Department is charged with recommending and administering state policies, plans, rules and regulations, guidelines and procedures in appropriate program, curricular, and service areas. A further assignment is the administration of pertinent federal and state funding programs.

According to the **Rules and Regulations to Govern the Administration and Operation of Special Education** (Article III, 3.01).

> Each local school district shall establish and maintain special educational instructional programs, resource programs and related services which meet the educational needs of children with the following exceptional characteristics:
>
> a) Auditory, visual, physical, or health impairment
>
> b) Speech or language impairment
>
> c) Deficits in the essential learning processes of perception, conceptualization, memory, attention
>
> d) Deficits in intellectual development and mental capacity
>
> e) Educational maladjustment related to social or cultural circumstances
>
> f) Affective disorders or adaptive behavior which restricts effective functioning
>
> However, the responsibility of making sure that local school districts meet these requirements is assigned in Article XIV, 14.01, which states that "The extent to which the local school district is fulfilling its responsibilities to exceptional children shall be determined by the Illinois Office of Education."
>
> It is clear that Illinois' legislative intent is that:
>
> 1) All children shall be provided an education appropriate to their unique needs.
>
> 2) The local school district has responsibility for providing the appropriate education.
>
> 3) The Department of Specialized Education Services, Illinois Office of Education, has the responsibility of monitoring and enforcing state requirements.

The financial problem for local school districts in complying with special education requirements was recognized in 1965 when HB 1407 was passed establishing formulas for state reimbursement to local school districts for the excess costs of educating students with exceptional characteristics. In succeeding years, as the amount and categories of reimbursement were modified, State appropriations bills for specialized education needs were funded at varying levels and compliance with educational mandates varied from one local school district to another.

During this period, the autistic child was rarely served in the public classroom. The usual practice was for local school districts, utilizing 14-7.02 provisions of the School Code, to apply for state reimbursement for excess costs and private day care programs generally provided for the education of the non-institutionalized autistic child.

With the passage of PL 94-142, the Illinois legislature enacted state legislation to bring the state into full compliance with the federal law and modified the **Rules and Regulations to Govern the Administration and Operation of Specialized Educational Services** to that same end. Significant changes involved (1) the clarification of terms and (2) the area of financial reimbursement.

Local educational agencies (LEA's) may utilize various options to provide educational services to students with exceptional needs:

(1) The local school district may provide services for resident handicapped children.

(2) A large school district may accept special education students from neighboring districts on a tuition basis.

(3) Several school districts may jointly form an organization to mutually provide for their combined special education needs. This is called a Joint Agreement.

(4) Ten Regional Special Education Service Centers in Illinois, geographically and administratively determined, may provide special education services to handicapped students whose needs cannot be met through any of the aforementioned structures.

(5) If because of his or her handicap, the special education program is unable to meet his or her needs, the child may be placed in a private facility. The school district in which the child resides shall provide necessary transportation and no more than twice its per capita amount when the tuition exceeds $4,500.

When residential placement is necessary, the LEA may contract for this service. Various other state agencies, depending on the individual case, may provide some financial support. However, if the legislature fails to appropriate sufficient funds, it is unclear as to who will meet the financial obligations. Current proposed legislative amendments are attempting to clarify financial liability among agencies.

V. **Joint Responsibilities:** From the foregoing discussion it is obvious that the Department of Mental Health/Developmental Disabilities and the public school system of Illinois have overlapping areas of responsibility in both non-residential and residential programs for autistic persons.

A major difference in their respective mandates is that the responsibility of the educational system is limited by statute to individuals between the ages of 3 and 21. The DMH/DD system has no such restriction, theoretically bearing responsibility from birth through adulthood for providing those services, in the least restrictive environment possible, which will help mentally ill or developmentally disabled persons to improve their level of functioning and social competence. The educational system is also more service specific, i.e., responsible for providing educational programs and those related services which are necessary in order for the individual to profit from the educational experience.

However, the definition of **educational and related services** has expanded so significantly in the context of P.L. 94-142, that many of the traditional DMH/DD services are now either directly or peripherally within the service mandate of the public educational system. Federal regulations contribute to the difficulties of resolving areas of responsibility. Part II of "Implementation of Part B, Education of the Handicapped Act" (**Federal Register,** August 28, 1977, Section 121a.5.b.8) states:

> **Seriously emotionally disturbed** is defined as follows: The term means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance: . . .(E) a tendency to develop physical symptoms or fears associated with personal or school problems. (ii) The term includes children who are schizophrenic or **autistic** (emphasis added).

Policy of the Illinois Department of Mental Health/Developmental Disabilities is that community agencies' service and concomitant financial priority shall be given those persons whose degree of emotional disturbance or developmental impairment places them at highest risk of extrusion from the community. Community agencies serving the developmentally disabled do provide service to the profoundly and multiply impaired (p. 27, this study). That 97% of autistic persons are eventually institutionalized would suggest that Community Mental Health Agencies would also be in the forefront of providing services to the autistic population which for purposes of PL 94-142 reporting is categorized as emotionally disturbed and is statistically at high risk of "extrusion from the community." As nearly as can be determined from the results of this study, no such service priority is extant.

The Rules and Regulations governing the implementation of Public Law 94-142 as previously quoted define autistic children as an emotionally disturbed population for whom the educational system must provide not only specialized education but related services including:

counseling services provided by social workers, psychologists, guidance counselors and similar qualified personnel as well as group and individual counseling with the child and his family. (121.a.b.2) In toto, these are personnel and service categories traditionally provided for within the mental health system to a population which meets the criteria of DMB/DD's highest risk category and accompanying service priority in the community mental health system. The provisions of P.L. 94-142 however, have engendered a shift of responsibility to the educational system without a concomitant stated policy change in the DMH/DD system.

At its semi-annual meeting in February, 1979, the National Association of State Mental Health Program Directors addressed policy issues and actions. The membership agreed that the Children's Division should study and analyze the impact on child mental health services resulting from designation of "Health Provider" status to state Education Agencies under P.L. 94-142. This action reflects the genuine and semantic confusion resulting from recent legislative actions.

Contradictions regarding financial responsibility as explicated in state and federal legislation compound the problem. In the federal arena, P.L. 94-142 requires that an appropriate education be provided at no cost to parents. On the other hand, Illinois' Mental Health and Developmental Disabilities Code (P.A. 90-1414, Section 105) states: "Each recipient of service of the Department and the estate of such person is liable for the payment of funds representing charges for services to such recipient at a rate to be determined by the Department in accordance with this act."

Financial responsibility of parents ceases when the child reaches majority. If the recipient, estate, or responsible relative are unable to pay the service charges, the cost shall be borne by the State except for the cost of clothing, transportation, and other incidentals which, when all other resources are exhausted, shall be assumed by the county of residence. The cost of clothing expenses are exempted from the county's responsibilities and, in the final analysis, are left unassigned (Section 115 of the Revised Mental Health Code).

The maximum charge for any family under the mental health code is $100 per month. The graduated scale is reproduced below:

Annual Income	Monthly Income	Number in Family (including recipient) 2	3	4	5	6	7	8 or more
$ 1,200	100	0	0	0	0	0	0	0
2,400	200	0	0	0	0	0	0	0
3,600	300	0	0	0	0	0	0	0
4,800	400	0	0	0	0	0	0	0
6,000	500	0	0	0	0	0	0	0
7,200	600	$ 6	0	0	0	0	0	0
8,400	700	14	0	0	0	0	0	0
9,600	800	24	$ 8	0	0	0	0	0
10,800	900	36	18	0	0	0	0	0
12,000	1,000	50	30	$10	0	0	0	0
13,200	1,100	66	44	22	0	0	0	0
14,400	1,200	84	60	36	$12	0	0	0
15,600	1,300	100	78	52	26	0	0	0
16,800	1,400	100	98	70	42	$14	0	0
18,000	1,500	100	100	90	60	30	0	0
19,200	1,600	100	100	100	80	48	$16	0
20,400	1,700	100	100	100	100	68	34	0
21,600	1,800	100	100	100	100	90	54	$18
22,800	1,900	100	100	100	100	100	76	38
24,000	2,000	100	100	100	100	100	100	60
25,200	2,100	100	100	100	100	100	100	84
26,400	2,200	100	100	100	100	100	100	100
27,600	2,300	100	100	100	100	100	100	100
28,800	2,400	100	100	100	100	100	100	100
30,000 and over	2,500	100	100	100	100	100	100	100

Annual income shall be gross income as defined in Section 203 of the "Illinois Income Tax Act", as now or hereafter amended.[1]

[1]Chapter 120, § 2-203.

When an Illinois resident between the ages of three and twenty-two exhibits exceptional characteristics so profound, complex or other unique that his/her needs cannot be met in the public school system, the **Rules and Regulations Governing the Administration and Operation of Special Education** state that the child may be referred for placement in a private or state-operated day program or residential facility. When the only appropriate resource is a residential facility, the provisions of federal and state laws are confused as to who shall provide services which are various defined as (1) medical/therapeutic or (2) related services as interpreted by 94-142. If the child's primary problem is serious emotional disturbance (and autism is so defined in the Federal Register) it would appear that under State Legislation, the Illinois Department of Mental Health/Developmental Disabilities is responsible for the costs of residential treatment with the parents, within their ability to pay, assuming some costs. However, if the child's ability to utilize the educational experience depends on the provision of related services, i.e., residential treatment, P.L. 94-142 states that the educational package, including related services, is provided at no cost to the parents.

Germane to the above discussion is a pervasive policy among all state agencies that each one is the payee of last resort. P.L. 94-142 does not propose that educational funds shall

supplant existing funding mechanisms, but, on the contrary, that state and local funding mechanisms shall maintain their level of financial support. Financial obligations of the Department of Children and Family Services, reimbursement claims under Title XX, Public Aid and Medicaid responsibilities and categorical funding under additional HEW programs are additional factors complicating a chaotic financial structure.

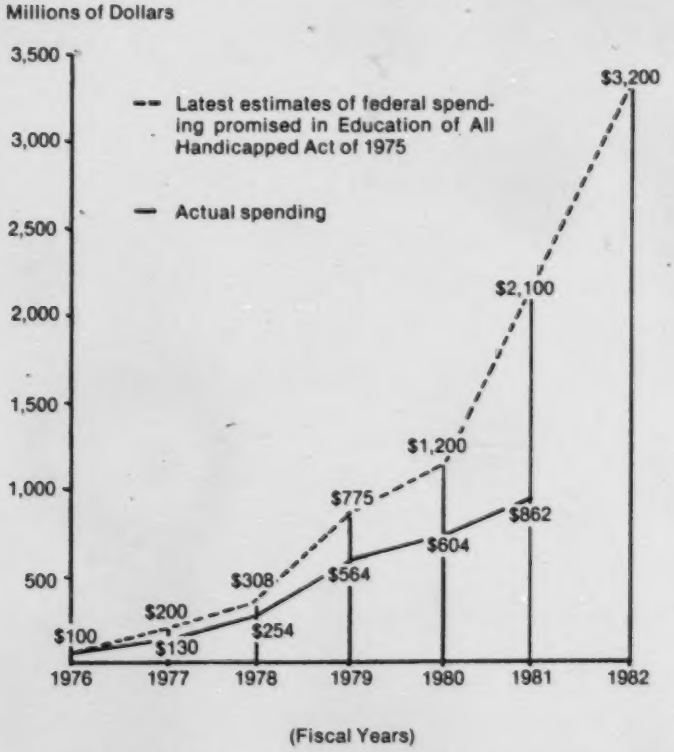
An interagency committee is currently meeting to address some of these problems.

The graph reproduced below represents one of the potential problems in over-reliance on the provisions of P.L. 94-142 to address all the needs of Illinois' autistic children.

NEWS CLIPPING. . .
THE PATRIOT, HARRISBURG, APRIL 7, 1979

THE FUNDING GAP

Difference between promised and actual spending for federal aid to education of the handicapped.



**President Carter's fiscal 1980 budget request (for fiscal 1981 spending)

VI. PROBLEMS AND RECOMMENDATIONS

Problem: **Service Responsibility** There is no locus of responsibility for services to autistic persons and their families.

Recommendations: (1) The state agencies primarily involved in service to autistic persons (The Department of Mental Health/Developmental Disabilities and the Department of Specialized Educational Services of the Illinois Office of Education) should include as an agenda item in their inter-agency meetings, the problems of providing services to autistic children.

(2) A representative committee should be designated to identify those fiscal, legislative, and policy constraints that militate against a solution to the problems.

(3) The committee should meet with parents of autistic children and direct service staff so that the difficulties they experience are fully understood.

(4) Actions to resolve the problems should be recommended.

(5) Parents in concert with other interested citizens and groups should take whatever actions are necessary and appropriate to assure that the recommendations are implemented.

Problem: **Services to Institutionalized Children** The current reality is that in early adolescence, the majority of autistic children disappear into an institutional system that does not provide for their potential growth and development.

Recommendations: (1) The Department of Mental Health/Developmental Disabilities and the Department of Specialized Educational Services of the Illinois Office of Education should delineate elements of an appropriate psycho-educational program and develop mechanisms to implement such program.

(2) "Related Services" as provided by either agency should be qualitatively evaluted in the light of the unique nature of the disability and necessary steps taken to improve the competency of diagnostic staff and professional persons responsible for program activities to achieve psycho-educational goals.

Problem: **Information and Referral** Although human service agencies routinely list information and referral as one of the services they provide, and although Illinois' Title XX Plan for Fiscal Year 1979 shows almost eight million dollars allocated to this function, parents of autistic children are consistently unsuccessful when they attempt to secure these services.

Recommendations: (1) The Illinois Society for Autistic Citizens and the Governor's Planning Council on Developmental Disabilities should closely examine Illinois' Title XX Plan and determine how information and referral funds allocated to nine human service agencies are utilized.

(2) As a result of their investigation, these same groups should require that designated information and referral funds are so allocated that they do in fact support at least one knowledgeable state resource providing information and referral services to the families of autistic persons.

Problem: **Service Deficits** The Illinois Autism Study has identified system deficits and gaps militating against the delivery of a comprehensive continuum of services to autistic persons. Implementation of the proposed recommendations to correct the identified problems requires a continued staff endeavor.

Recommendations: (1) The Governor's Planning Council on Developmental Disabilities and the Illinois Office of Education should continue funding staff positions necessary to begin implementation of the recommendations occasioned by the study.

(2) The Autism Advisory Council should establish a priority ranking of the recommendations to determine the direction of the second year's work.

PROPOSED CONTINUUM OF SERVICES

FOR

AUTISTIC PERSONS

Prevention	Support of research
	Medical Care: Immunization; Prenatal Care
	Activities to reduce secondary handicaps
Early Diagnosis	Professional knowledge of autism
	Network of diagnostic resources
	Public awareness of autism
	Information/referral services
Early Intervention	Parent/infant programs
	Parent training programs
	Preschool programs
	Parent counseling resources
	Medical/diagnostic resources
	Dental Care
	Nutritional/dietary evaluation and counseling
School Age Services	Diagnostic resources
	Educational Programs
	Leisure/recreation programs
	Pre-vocational assessment/training
	Vocational assessment/training
	Residential resources
	Medical care
	Dental care
	Nutrition/dietary evaluation and counseling
Adult Services	Vocational assessment and training
	Employment
	Continuing education opportunities
	Leisure/recreation resources
	Residential resources
	Medical/dental care
	Financial assistance
	Legal resources
Family Services	Information/referral services
	Counseling resources
	Financial assistance
	Leisure/recreation opportunities
	Trained babysitters
	Trained homemakers
	Respite care resources
	Legal counseling/advocacy
	Crisis resources

PREVENTION

> . . .the cause or causes of autism and the physiological mechanisms which underline its development have still to be established. There are good leads on all these questions and the knowledge accumulated from research during the last decade has considerably sharpened the issues to be studied during the next ten years. While we are still far from complete understanding of childhood autism, we are very much nearer that elusive goal. . .(Rutter, 1978, p.20)

I. **Research Efforts.** Traditionally, two classes of prevention have been distinguished: primary and secondary. Primary prevention tries to forestall some harmful process or event. Secondary prevention concentrates on early identification and treatment, so that the consequences of the potentially debilitating process or event either do not appear or are rendered less harmful (Brewer and Kakalik, 1979).

Inasmuch as autism is generally idiopathic in origin, there are no specific preventive measures which can forestall its occurrence. The findings of most current research support a theory of multiple causation. It is also possible that its symptoms are manifestations of an unrecognized disease process. Furthermore, the current state of knowledge demonstrates that autism frequently co-exists with other disabilities of development, such as mental retardation and specific neurological diseases.

A most important activity relative to prevention is to support an increased research effort. In FY '76, 50 different major programs and hundreds of state and local programs together expended at least $7 billion for handicapped youth; however, as nearly as can be determined, only 1% of government funds is targeted for prevention (Brewer and Kakalik, 1979).

Responsibility for preventive programs on the federal level resides in Federal Institutes within the National Institutes of Health. The National Institute for Child Health and Development, the National Institute for Neurological Diseases and Stroke, the National Institute of Allergy and Infectious Diseases, and the National Institute of General Medical Sciences conduct studies which have the greatest potential for ascertaining the causes and treatment of autism. Information about research conducted in the private sector is not available.

Maternal and Child Health and Division of Services to Crippled Children also include prevention as a general goal of their programs. The level and quality of research in these programs is difficult to assess.

The perinatal program of the National Institutes for Neurological Diseases and Stroke has for many years been conducting studies of neurologically and sensorially handicapped children. The allocation of personnel and financial resources to analyze and extract the benefits from this data is, however, inadequate.

Among recommendations made toward improving prevention of children's handicapping conditions, is that a single federal agency should have the responsibility of prevention as a service. To fully assess the implications of such structural change is not possible within the purview of this study. However, the merits of such proposal should be fully explored.

II. **Secondary Prevention** Secondary prevention requires early diagnosis of autism, prompt institution of remediation measures, and an extensive and extended range of services designed to reduce the severity of the handicap. These activities are addressed in subsequent chapters.

III. PROBLEMS AND RECOMMENDATIONS

Problem: **Primary Prevention** There is minimal financial commitment to research in primary prevention of developmental disabilities, among them the disability of autism.

Recommendations: (1) Special educators, as well as special interest groups such as the National Society for Autistic Children should actively lobby for increased support of research as a priority allocation of federal tax dollars.

(2) Concerned groups such as those mentioned and the Governor's Planning Council on Developmental Disabilities should examine Illinois' research programs supported by federal funds such as Community Mental Health Centers, Maternal and Child Health, and Title XX to determine whether these are cost effective programs.

(3) Parents of handicapped children as well as groups such as special eduators should support programs for gifted children. These may be the children who, provided the necessary education, will contribute most significantly to the understanding and prevention of handicapping conditions.

Problem: **Secondary Prevention** A component of secondary prevention strategy is public awareness of the disability. Among the purposes of the National Society for Autistic Children is the development and dissemination of information about autism. State and local chapters of the National organization also provide public information about the disability. Despite these efforts, lack of information and misconceptions about autism are promulgated in the academic system. Just as the informal network or word-of-mouth is often the vehicle by which parents first learn about the syndrome so does the professional network continue to pass on outmoded theories about autism.

Recommendations: (1) The Illinois Society for Autistic Children should launch a membership campaign to increase public awareness and to strengthen efforts of the national organization.

(2) The Illinois Society for Autistic Children should develop a roster of qualified speakers and seek out opportunities to present programs to civic and professional groups.

(3) The Illinois Society for Autistic Children should print and distribute a newsletter at regular intervals to concerned citizens and groups including the public media.

(4) The Illinois Office of Education, Department of Specialized Education Services should develop a position paper summarizing current theory relative to causation, symptomatology, and remediation of autism. Printed in pamphlet form, this should be distributed to Child Find Personnel, Directors of Special Education, and other appropriate target groups.

(5) Although quick tips in workshops are not a substitute for basic education, workshops sponsored by the Department of Specialized Educational Services, Illinois Office of Education should include a variety of presentations relative to the disability utilizing expertise available both within and outside the state.

(6) The Department of Mental Health/Developmental Disabilities should identify autism as a distinct disability in communications emanating from their office.

(7) The Governor's Planning Council on Developmental Disabilities should provide for orientation of its staff and Council members relative to the disability.

Problem: **Early Diagnosis** Early diagnosis and institution of appropriate remediation measures as secondary prevention strategies are the exception rather than the rule.

Recommendations: (1) Medical school faculties should be encouraged to include basic information about autism in standard medical school curricula. Directors of residency programs in pediatrics, psychiatry and family practice should include theoretical information about autism in their training programs, and insure that trainees have the opportunity to observe affected children. Programs of continuing medical education, particularly those aimed at pediatricians, family physicians and psychiatrists, should periodically include information regarding diagnosis and management of autism.

(2) Personnel staffing public health clinics should be provided both in-service and continuing education opportunities to enhance their skill in detecting early indications of developmental problems.

(3) Physician extenders such as nurse practitioners should be legally recognized so that a more effective and equitable distribution of medical expertise is available to Illinois residents. A thorough evalua-

tion of infant progress requires a time commitment rarely available in routine infant checkups. The practice of preventive rather than corrective medical care requires extending the supply of health professionals. The penalty of failure to utilize the nurse practitioner's expertise is a diminished level of health care for children.

(4) Administrators of Special Education programs as well as professional staff assigned to preschool programs should participate in inservice training programs which include information about differential diagnosis of developmental disabilities and programming needs specific to the autistic child.

Problem: **Prenatal Care and Immunization** Recommended public health measures to decrease the incidence of developmental disabilities are not uniformly implemented.

Recommendation: Despite the lack of knowledge about the causes of autism, preventive measures affecting the well-being of all children should also be vigorously supported. Such measures include:

Immunization Preliminary to any pregnancy, there should be immunization against those diseases for which an immunizing agent has proved effective. Although there is no causative factor established between rubella and autism, there is a correlation between maternal first trimester rubella and the incidence of infantile autism (Stubbs, 1978). Therefore, as a preventive measure, it is particularly important that female children be immunized against rubella. Legislation already requires evidence of immunization for pupils entering the public and private school systems. To achieve a satisfactory immunization level for all children requires:

(a) Ongoing public education programs utilizing a broad spectrum of public media about the importance of immunization and pre-natal care. Educating potential parents as well as alerting children about their own immunization status requires a multi-faceted approach. Introducing immunization commercials into children's television programs is one method. Voluntary service clubs, who have a network of local chapters such as Lions, Kiwanis, and Junior Chambers of Commerce, could be approached to adopt dissemination of immunization information as a public service project. The private

and public health sectors and the public school system should join in an intensive campaign to increase immunization levels.

(b) The school systems must consistently enforce legislative requirements requiring immunization evidence as a condition for school attendance.

(c) Both public and private health sectors should aggressively promote and follow-up on immunization schedules for children under their care. Private medical care providers should inform parents of publicly financed immunization services.

PRESCHOOL EDUCATION

> Responsibility implies always asking whether one is justified in intervening and considering what value the goal has for both the individual and society. (Hayden and McGinness, 1977)

I. **Issues in Preschool Education** Preschool education is defined in the Federal Register, May 4, 1979 as "education provided from birth until the age at which the state provides elementary education."

Before the non-handicapped child reaches school age, he has accumulated a wealth of knowledge. Within some broad outlines, he has profited from the interaction of his inner and outer environment, developing skills in communication and in social response and some ability to control his behavior.

In contrast, the autistic child has been unable to make similar educational progress. The repertoire of skills which are usually acquired by other children during the first six years of life are either totally lacking or are present in uneven or distorted form. The failure to communicate meaningfully and to make appropriate social responses as well as the propensity toward problem behaviors constitute not only a failure to achieve normal developmental milestones, but a cumulative educational deficit.

Inasmuch as one of the purposes of prescriptive education of the handicapped child is to prevent or reduce the development of secondary handicaps as a result of the primary handicap, it is then particularly important that education for the autistic child be instituted as early as possible in the preschool years.

The idea of birth registry is generally distasteful to the American public. It gives substance to the nightmare of totalitarian control. However, the goal of an educational and health system which would successfully address the needs of each person as a unique individual would potentially sanction just such a system.

The question of society's control over the welfare of its children is not resolved, but the mechanisms for early identification of developmental anomalies and of instituting intervention measures exist now within the health care and the educational systems. The obvious and readily discernible disabilities present at birth are automatically within the purview of the medical system. However, as is apparent from increasing litigation, medical authority may be challenged by parental authority. Although educational systems are charged with the responsibility of identifying and providing for preschool children in need of specialized educational services, this process also is ultimately a voluntary one requiring parental cooperation.

II. **Early Identification** Federal and Illinois legislation requires that school systems actively seek to identify the handicapped preschool population. The usual methods of informing the public about the need for identification and screening of preschool handicapped children have met with varying levels of success. To obviate the problem, in one community, volunteers canvassed house-to-house to secure the names of all preschoolers and to secure information indicative of the possibility of a handicapping condition. In other communities, school systems have encouraged parents to register all preschoolers with the public schools. In one community, utilizing the Employment of Older Americans Act, the school system has hired persons to conduct a total household survey to identify preschoolers at risk. In those communities promoting registration of all preschoolers without regard to actual or presumed disability, there has resulted an increased number of registrants, attributable in part to the fact that parents were more cooperative when all children were included. Reluctance to identify their family as separate or different was judged as a negative factor militating against the success of public media campaigns stressing the abnormal characteristics requiring intervention by the system.

As evidenced by recent legislation, public opinion increasingly supports the position that as soon as there is substantial evidence that an infant or child's social, cognitive and emotional growth is significantly and consistently deviant, there should be available a range of services designed to ameliorate the problems and to forestall increased deviance and the development of additional problems for both the child and his family. Primary among the recommended services is an educational system available from birth through 21.

Generally, developmentally delayed preschoolers are educated in non-categorical classrooms. Among the reasons for continuing this procedure are that it provides for ongoing diagnostic assessment and avoids the dangers of premature and inaccurate labeling and inappropriate programming.

Although it may be practical, given the current realities, to address the needs of older severely/profoundly handicapped children in special classes, educating preschoolers in a non-segregated setting provides an opportunity to evaluate the presumed benefits of integration. Children learn from each other; segregation denies handicapped children exposure to normal children and the chance to model their behavior on that of normally developing peers. Staff expectations may also be restricted when their exposure is limited to classes of handicapped children.

Given current legislative and funding mechanisms, however, the availability of

preschool education is mandated only for the handicapped which means that segregation rather than integration is the norm.

III. **Preschool Programs in Illinois** There are three federally funded programs available for education of the preschool handicapped child: the Head Start Program, the Preschool Incentive Program (94-142), and the Early Education for the Handicapped Program.

Head Start The purpose of the Head Start Program is to provide diagnosis, education, health and nutrition services to three to five-year-old children of economically disadvantaged families. Rules and regulations stipulate that 90% of the registered children must come from families with incomes below the poverty index. It further stipulates that in each state, 10% of the enrollment shall be reserved for preschool handicapped children and that services shall be provided to meet their special needs.

In Illinois there are 35 full year Head Start programs serving 19,200 children. According to a 1978 report compiled by the Department of Human Services, 10.28% or 1,019 of the enrolled children in Illinois Head Start Programs have been diagnosed as handicapped.

Early Education for Handicapped Children The purpose of this program is to assist state and local education agencies in developing model preschool and early education programs for handicapped children. Projects are expected to be designed so that they can be replicated in other communities. In Illinois there are twelve projects funded under this legislation, six for the 0-3 age group, five for the 3-5 age group, and one for the severely and profoundly involved 0-8 age group.

Preschool Incentive Grants Under 94-142 legislation, when a state has in effect a policy assuring a free and appropriate education to all handicapped children and has otherwise complied with requirements of the legislation, it may apply for Preschool Incentive Grants for special education and related services to 3-5 year olds. The sum of $300 per child is the maximum amount available as the federal share of providing such services.

In Illinois, legislation requires that all handicapped children between the ages of 3 and 21 shall have the right to a free appropriate education by September 1, 1980. The FY '80 application for preschool incentive funds (Part B, Education of the Handicapped Act as amended by P.L. 94-142) states that an estimated 20,000 three to five-year-old handicapped children will be served in the 1979-80 school year.

0-2 Programs Illinois' 80th General Assembly amended Article 10-22.30 of the **School Code,** Section 10-22.38 (handicapped preschool children) to state that local school districts are permitted to "establish and maintain or to cooperate with other educational, governmental, social and volunteer agencies in the establishment and carrying out of programs

designed to identify and ameliorate mental, emotional, physical and social-cultural handicaps in preschool age children below the age of three that would prevent such children from taking full advantage of regular school programs." The legislation further states that "no school district is eligible for state reimbursement under Article 14 or Article 18 for programs provided to handicapped children under this section."

In FY '79 in Illinois, there are 273 children in the 0-2 age group being served in the public education system.

Department of Mental Health/Developmental Disabilities The Department of Mental Health/Developmental Disabilities provides funds through its grant-in-aid program to agencies engaged in early identification of preschool developmentally disabled children. The services were developed originally to provide for early identification of low incidence handicaps and to provide back-up services in those areas of the state where there were not organized community efforts.

Presently there are approximately ten or fifteen funded programs, the purposes of which are to encourage the early identification of low incidence handicaps and to institute appropriate remediation measures. Generally, the programs are located where there exist diagnostic and professional resources as well as local interest in making such programs available.

Whenever possible, services are paid for under third-party coverage or under Medicaid. Department funds pay for services to children who are not covered under other mechanisms.

Children are referred into the program from the high-risk infant programs, from family support units, or as a result of other case finding efforts.

Information systems do not produce a non-duplicated count of the number of children served in this program; therefore, the number of children served per year is lacking.

IV. **Content of Educational Intervention** On the basis of current etiological theories and recommended remediation techniques, a preschool program for autistic children should operate within a developmental framework:

(1) Knowledge of normal developmental needs demands that all preschoolers have ample opportunity for physical activity. Presumption of neurological impairment or delay in autistic children requires that remediation specifically include periods of therapeutically determined physical activity.

(2) Knowledge of normal developmental tasks emphasizes the need for an environment conducive to accomplishment of developmental tasks. Presumption of dis-

ordered sensorimotor integration in the autistic child demands a learning environment addressing this developmental need on an individual prescriptive basis.

(3) Knowledge of the normal sequence of cognitive development dictates an environment providing ample and varied stimuli. Presumption of a developmental delay or impairment of cognitive development in autistic children requires that the educational program provide cognitive stimulation appropriate to the child's mental age and his unique method of processing information.

(4) Knowledge of normal cognitive, emotional, and social developmental processes emphasizes the importance of the child's developing a method of meaningful communication. Evidence of impaired or nonexistent communication skills in the autistic child demands a program of remediation for this deficit.

(5) Knowledge of developmental norms for acquisition of social behavior indicates the necessity of an environment which encourages the development of appropriate social behavior. Evidence of inappropriate social behavior and of age inappropriate behavior in the autistic child requires educational strategies to stimulate appropriate social interaction and to reduce inappropriate social behavior.

Preschool programs for the autistic should be based on:

(1) A structured day with scheduled time for non-directed activity.

(2) Brief time periods allocated to any one activity, extended as the year progresses and according to the goals and progress of the individual.

(3) Parent involvement.

(4) Adequate numbers of trained staff.

Physical facilities should include:

(1) Space and equipment for motor activities, indoors and outdoors.

(2) Space and materials for pre-academic work.

(3) Equipment and material providing contrast in texture, size and form.

(4) Readily accessible toilet facilities.

Program content will also reflect the philosophy of staff and parents. Despite differences regarding the precise etiologies of the autistic syndrome, there are broad areas of agreement which have implications for preferred remedial measures.

Areas of agreement are:

(1) The precipitating factor is physiological; this may be failure of the essential systems to develop, aberrant development of essential systems, delayed development of essential systems or any combination of these.

(2) The basic pathology results in additional handicaps.

A major objective of the eduational program is to establish those procedures which will encourage communicative abilities, to increase ability to accurately process information coming from the environment, and to experience pleasure as a result of these activities. Generally this means intruding into the world of the autistic child, developing an acute sensitivity as to what his actions and reactions mean, recognizing very small gains.

The normal two-month old has learned some communication skills and consequently some control over his environment. He cries. His mother picks him up and talks soothingly to him. He stops crying. His mother feeds him. He goes to sleep.

In contrast, the two-year-old autistic child who is hungry may communicate by taking up a stance in front of the refrigerator. He makes no verbal utterances. His facial expression is unchanged. Unless someone happens to be in the kitchen and understands why the child is standing in front of the refrigerator, there will be no response. His lack of communication such as pointing or talking denies him control over his environment. The lack of response to his subtle messages offers no encouragement to a continued effort at any kind of communicaton. Staff utilized in preschool programs need an acute sensitivity to primitive levels of communication and awareness of the urgency of responding to and rewarding any attempt the child makes toward communicative and social exchange.

Various disciplines contribute to the effectiveness of a preschool program:

(1) Occupational therapy
(2) Speech therapy
(3) Psychology
(4) Social Work
(5) Pediatric nursing
(6) Physical education therapy
(7) Special education
(8) Music/art therapy
(9) Child development
(10) Medicine: pediatrics, neurology, family practice, psychiatry

These diverse skills and knowledge are useful in developing an adequate prescriptive program and in implementation of the program. Also an effective program will incorporate a variety of remedial activities throughout the day. Additionally, the multi-disciplinary approach yields dividends in the spill-over of knowledge as one professional learns from another.

It is assumed that infants who are enrolled in an educational program because of extreme passivity, lack of appropriate social response, or prolonged screaming and agitation have had a thorough medical evaluation. No remediation should be undertaken until such evaluation has taken place.

Upon referal, the infant should be observed in his own home for a period of two hours on at least three different occasions by a child development specialist. Assessment of the child and of parent/child interaction will dictate the kinds of remediation to be provided. Parents need (1) jargon-free instruction about the developmental norms and developmental needs of all children, (2) concrete methods for providing the environment and activities necessary for optimal development, (3) clear and simple explanations of how parents train children -- and of how children train parents, (4) help in perceiving their own interactions, (5) practice in changing their interactions, and (6) successful experience as a result of change.

The autistic child may very well program his parents to his own detriment. The "very good" baby is often an overly passive baby. Infants within the range of normal development reward their parents' cuddling, talking, or stroking by smiling and otherwise showing pleasure. These responses tend to increase the parents' overtures to the child. When an infant is unresponsive, parents usually decrease their social attention to the child because there is no reciprocal pleasure evidenced. Thus, the autistic child may lack the stimulation which he may need even more than the normal child.

Infants developing within developmental norms also begin to make demands almost immediately, crying, for instance, when they are hungry. The undemanding child, on the other hand, does not subject his parents to the annoyance of his screams, and there is a resultant decrease in the amount of parent/child interaction which is necessary for his development. The satisfaction of meeting the child's demand for food or comfort is denied the parent of an overly passive child; fed or unfed, he remains pretty much the same.

At the other extreme, the infant who cries unconsolably for long periods of time sets up, for different reasons, a similar environment. Again, the parent is denied the satisfaction of meeting the infant's needs if he screams, fed or unfed, dry or wet, rocked or ignored. When the child is quiet, the parent is most unlikely to disturb this rare peace by initiating any kind of activity. The autistic infant may actively arch away from the parents and scream if he is held; from this behavior, the parent learns to avoid the normal holding, rocking and hugging accorded other babies.

If the infant is unhappy and makes everyone else unhappy whenever his routine at

home varies or if he is taken out for a visit, the parent typically responds by adhereing to an unvarying routine and by keeping the baby at home and staying there with him.

In all the above parental responses, the stage is set for the potential tyranny of the autistic child. Parents become disappointed, puzzled and resentful. This is not the way it was supposed to be.

V. **Range of Programs** The range of educational programs available for early childhood education should include:

(1) A home-based program: A child development specialist visits the home on a regular schedule, at least weekly, to observe, establish with the parents goals to be worked on, demonstrate methodology, and evaluate progress. The child development worker also provides an opportunity for the parents to express their concerns and their needs and serves as a linkage to other community resources.

(2) Parent/child classes: Parent(s) brings child weekly or semi-weekly to the school. Parent and staff evaluate problems and progress, determine goals to be addressed in the next time increment, and set up procedures to attain the goals.

(3) The child attends early childhood program and parent(s) come regularly to meet with staff or the staff makes home visits to assure a collaborative effort.

As early as possible, autistic children and their parents should be provided an appropriate psycho-educational program. At the very least, for two years before enrollment in the regular school program, the autistic child needs to experience a group setting outside his home. The experience is necessary to prepare him for separation from home, to provide him the experience of functioning in a small group, to establish some necessary habits such as sitting, paying attention, and responding to simple directions.

Preschool programs are generally limited to a maximum of four hours daily. This amount of time provides for something to take place as far as food is concerned and for improving eating skills. It provides enough time for a range of behaviors to be exhibited and addressed. It also means that the program does not interfere with the sleeping needs of preschoolers.

Some programs are limited to two hours which doubles the number of children who can be served in the same amount of time.

Day Care programs for children of working mothers, on the other hand, need to be available from 7:00 a.m. to 6:00 p.m. Illinois' day care programs are generally available only in urban areas, rarely in rural areas.

The chart below illustrates a continuum model for preschool education.

Pre-School Educational Programs

Frequency	Duration	Participants	Staff Ratios
Daily	Full day	Pre-schooler-(Parent weekly)	1:3
Daily	4 hours	Pre-schooler-(Parent weekly)	1:3
Semi-weekly	2-4 hours	Pre-schooler and Parent	1:5
Weekly	1-2 hours	Infant and Parent	1: 10-12

VI. PROBLEMS AND RECOMMENDATIONS

Problem: **Preschool Programs** The needs of preschool autistic children are not systematically addressed within the current system.

Recommendations: (1) The Department of Mental Health/Developmental Disabilities should assume primary responsibility in its community based system for the 0-3 year age group of autistic children.

(2) The Department should develop and fund necessary support services for the preschool autistic child and his family, including trained home-makers, trained baby sitters, and respite care.

(3) The Department should train or re-train staff as necessary to assure that the care and education provided are appropriate and effective.

(4) The Department of Mental Health/Developmental Disabilities and the Department of Specialized Educational Services of the Illinois Office of Education should plan jointly and cooperatively for the education of the pre-school autistic child from age 3 on.

Problem: **Lack of year-round programming** Regression is likely unless there is continuous year-round programming for the autistic child. Yet public school summer programs when they are available, are usually limited to six weeks.

Recommendations: (1) Year round programming should be available for all preschool and school age autistic children. . .The Department of Mental Health/Developmental Disabilities should take a census now of where there are pre-schoolers unserved and establish as a priority that community agencies shall provide or supplement currently available summer programs so that year round programs are available.

(2) The Department of Specialized Educational Services of the Illinois Office of Education should study the implications of extending summer school programming to a uniform eight week session.

EDUCATION FOR THE SCHOOL AGE CHILD

> The aims of education for any handicapped children are: to help overcome or compensate for the primary disability; to reduce or remove the secondary behavior problems; to improve the level of self care; to teach practical, academic and occupational skills; to help the handicapped person to derive as much satisfaction and enjoyment from life as possible. (Wing, 1976)

I. **Physical Settings** Within the Illinois public school system, some autistic children are currently being educated in self-contained classrooms located in regular public school buildings. Others are being educated in classrooms located in Special Education buildings housing only classrooms for children with various handicapping conditions. Some non-public school programs are located in settings where programs are provided only to autistic children or those with autistic characteristics. Other private programs are located in segregated buildings providing programs for various handicapping conditions.

The success of Illinois programs does not seem to bear any relationship to the settings in which they occur. Theoretically, a non-segregated setting would be the optimal setting:

(1) Location within a regular school building encourages integration with "normal" students. Association with non-autistic children is desirable because they may serve as models for autistic children and promote appropriate social behaviors and interaction.

(2) For the autistic child who has isolated abilities or is generally higher functioning, integration into appropriate classes is readily available.

(3) The whole thrust toward normalization supports maximum integration of handicapped and non-handicapped children.

The reality is that children being educated in regular public school buildings may be as isolated as any in a segregated setting whereas autistic students served in a separate building may be making regular and frequent trips into the community, interacting in stores, at zoos and on buses with non-autistic persons.

Autistic classes located in regular public school buildings may have greater resources available to them such as gymnasiums and varieties or outdoor play equipment. On the other hand, some autistic classes in a segregated setting may experience greater availability of space and equipment which is not shared with a large school population. Programs in segregated settings may also benefit from the greater flexibility inherent in

freedom to use space to achieve programs goals rather than to accommodate the needs of diverse educational units.

Personnel resources in an integrated setting may exceed those available in a segregated setting and disciplines that are in short supply may be more effectively utilized. Segregated settings sometimes are especially effective in promoting development of a well functioning team. The staff in non-segregated settings, however, often display these same characteristics of effective group function and mutual support.

Location in a regular school building does not necessarily effect integration of special education staff with personnel employed in regular classrooms. On the contrary, staff of the autistic classes located in the regular public school buildings are frequently as isolated from other staff as if they were on a separate campus. The daily schedule rarely provides time for casual contacts with staff of regular classrooms. Unless there has been a successful orientation of all students and teachers, autism classroom teachers and students may also be avoided by reason of their differentness, children because of their behavior and staff because of the nature of their assignment.

An example of successful integration identifies some of the processes which increase the likelihood of success. In one school system, staff and administration prepared for a proposed move to a regular school building as follows:

(1) Autistic children were filmed showing the behaviors characteristic of the syndrome.

(2) The parents of the children were shown the films and either consented to or refused written permission to have their child's video tape shown publicly.

(3) One staff member from the autism class showed the film and held a discussion about autism with the parents of all children enrolled in the school. Another staff person performed this same function with the "regular" teachers. A third staff member took this same responsibility with the student body.

The autistic classes are functioning well in this building. They are combined as far as is practical with regular classes for physical education and gym. Children in the primary grades vie for the honor of being assigned as a "buddy" to an autistic child and spend limited amounts of the school day in the autistic classroom. The parents of the normal children are interested and supportive of the program and have so far expressed no negative opinions. The teachers began to know each other before the opening of school and good communication and cooperation have continued.

One other factor which may have some relevance to the physical location of autistic

classrooms is interpretation of "least restrictive environment" as mandated in P.L. 94-142. A unilateral decision that education in any one of these settings is synonymous with "least restrictive environment" would on occasion subvert the intent of the law that each child should receive an "appropriate education." In the absence of evaluative information, interpretation of "least restrictive environment" should remain open, and be based on individual assessments and the exercise of common sense.

II. **Educational Programs** Results of a limited number of evaluation studies indicate that educational environments are most successful when they are structured, organized, and logical (Ritvo, 1976). These characteristics are applied to the school day itself; to the scheduling of activities; to the analysis of the task to be learned.

Structure of the school day encompasses both timing and curriculum content. Periods of one-half hour are usually the maximum or tolerable level for any single activity--and for cognitive activities, 15 minutes may be more than an individual child can tolerate. The sequencing of activities is a further consideration. For instance, observations have been made that children accomplish cognitive and language tasks more successfully in the morning (California State Department of Education, 1977). Sequencing may further utilize the characteristics of the disability itself. For example, the physical contact that autistic children usually enjoy is tickling or rough housing. Scheduling this kind of activity after a less pleasant and more demanding one takes advantage of the characteristics inherent in the syndrome. Lunch time and snack time as pleasurable activities can also be scheduled to maximum advantage.

By their very nature, well developed IEP's incorporate the recommended elements. If a long term goal, for instance, is independent feeding, short term goals based on task analysis supply the underlay of structure, organization, and logic.

The choice of methodology should be a conscious one. Behavior modification, operant conditioning and developmental theory require systematic and consistent application. Logic further requires assessment and revision of goals, progress, and methodology at appropriate intervals.

If the specific cause or causes of autism were known, the direction of educational approaches would be clarified. In the absence of such information, most successful programs throughout the country assume a theoretical framework, empirically derived. Among these are:

Neurodevelopmental: Educational strategies are based on the view that autism results from neuroperceptual lags, dysmaturation, and lack of integration (Shapiro, 1978).

Perceptual training techniques that are aimed at increasing integration and activities to provide tactile and vestibular stimulation are emphasized in these programs. Critics of this methodology note that unless these strategies are combined with direct training for necessary life skills, progress toward the latter goals does not occur.

Developmental-Cognitive: Educational programs are based on a causation theory that recognizes a disorder of the central nervous system in combination with the interplay of the environment. Remediation includes a well developed diagnosis from a multidisciplinary team, development of an individual prescriptive program, and coordination of school and home in a total environment effort toward remediation.

Learning Theory: Educational programs based on learning theory do not include etiology as relevant to their interventions. Their focus is on demonstrated behavior and stimuli promoting the behavior. Operant conditioning and behavior modification techniques are the primary tools utilized.

Distillation of current educational programs that, on a relative scale, are most effective isolates some common elements of a theoretical framework, as follows:

Autism is most likely due to biological and neurological brain abnormalities. These difficulties manifest themselves in perceptual inconstancy, speech and communication problems and other symptoms of sensory integration. Intervention must be based on an evaluation of physical, environmental, and cognitive properties. The program of intervention should include the family to the maximum extent feasible in achieving mutually determined goals. Methods of achieving goals should reflect the idiosyncratic nature of the particular child as well as empirically validated theories of learning. The kinds of staff employed should reflect the need for diversity, and the number of staff employed should be sufficient to carry out the program.

Educational Philosophy: Responses to questions about the philosophical basis for educational methodology employed in programs for autistic children in Illinois tended to favor some variant of behavior modification. Some teachers were puzzled by the question and were apparently not clear about why they were employing or not employing any particular technique. There were teachers who immediately explained that autistic children required a range of methodologies, that what worked for one child was not successful with another and that the individual child varied in his responses over a period of time.

Among those who relied heavily on behavior modification, there was discrepancy in data keeping. Decisions to record or to not record data were sometimes conscious ones. Some professionals viewed this as detracting from the staff's effectiveness. Others be-

lieved that this was the only way to accurately evaluate progress or failure. The use of data recording was unfamiliar to other staff even though they subscribed to a behavior modification philosophy.

The educational materials used in the classrooms were often developed by the staff. Generally, commercially developed materials were found to be inappropriate unless they were adapted. The Distar reading series was often mentioned as appropriate and useful. Many teachers stated that the paucity of available curricula materials was a problem.

Finding enough curriculum content to keep the school day meaningful was another difficulty frequently mentioned. Numerous studies document that autistic children lapse rapidly into irrelevant or stereotyped solitary activities unless they are engaged in purposeful tasks. Behavior modification techniques rely on external reinforcement to effect desired behavior -- within this framework, maintaining on-task behavior for a classroom of autistic children more than 50% of the time requires sufficient personnel, clear goals and sophisticated methodology. The Maudsley Study. (Bartak & Rutter, 1973) which included measurement of how much time children spent in planned activities in three different units utilizing three different treatment approaches, found the highest production in a structured unit was 59% with a decrease to 29% in a unit characterized by free play and a non-directive staff.

The lack of self-motivation and self-initiated activities of autistic children requires an extraordinary expenditure of energy from classroom staff. Given the nature of the disability, the additional tasks of developing materials and evaluating classroom and individual activities require the time and effort of more than one solitary teacher.

III. **Personnel** In the public school system, special education teachers are the professional group most directly involved with the autistic child's education. It is the responsibility of the special education teacher to develop in concert with parents and other specified professional staff the individualized educational program (the IEP) to implement the program, and to evaluate progress in achieving IEP goals. If there are non-professional staff employed, the teacher supervises performance of their duties. Sometimes the teacher is in close communication with the parents and also serves in a therapeutic/counseling role to them. Planning, scheduling and maintaining administrative and education records are among the other duties of the special education teacher. Keeping abreast of developments in the special education field and in changing legislation is also part of the job.

Included in the information gathered during site visits were responses to an open-ended question asking about desirable or necessary personal characteristics for teachers

of autistic children. Both administrative and direct service personnel were queried. The responses are listed in descending order of frequency, as follows:

Physical energy (10)

Flexibility (6)

Patience, Intelligence, Enthusiasm, Sincerity (8 each)

Firmness, Sense of humor (5 each)

Creativity, Warmth, Self confidence, Reasonableness (3 each)

Self-knowledge, Consistency, Rigidity (1 each)

During the site visits made to classes identified as serving autistic children, the question was also asked to both teachers and administrators, "Are teachers of autistic children adequately prepared?"

It is the one item that (with a single exception) was answered unanimously "no." Comments included "What preparation?" to "It is incredibly bad." There are some well prepared and excellent teachers in both the public and private classrooms. There are also teachers who are floundering about in unfamiliar territory. They do not know which diagnostic procedures might be helpful in identifying the special characteristics of the children in their classrooms and although their academic training may have included a survey of the principles of behavior management, they do not have a thorough grasp of the procedures. The problem is not lack of trying, but rather lack of the tools needed to be effective.

IV **Teacher Preparation: Public Schools** Minimum requirements for teachers employed in Illinois public schools are established by law. Article XIV-9.01 of the **Illinois School Code** states:

> No person shall be employed to teach any class or program authorized by this article who does not hold a valid teacher's certificate as provided by law and unless he has had such special training as the Superintendent of Public Instruction may require.

Additional requirements for special education teachers are specified in the **Rules and Regulations to Govern the Administration and Operation of Special Education,** Article XII-12.02. Professional instructional personnel shall qualify under any one of the following circumstances:

(1) Hold standard Special Illinois Teachers Certificate, Type 10, in the area of responsibility

(2) Hold standard Illinois Teachers Certificate and receive approval outlined by the Illinois Office of Education in the **Special Education Certification and Approval Requirements and Procedures.**

(3) Hold standard Illinois Teachers Certificate and receive approval by the Illinois Office of Education for specialized functioning in relation to a special education program.

(4) In Chicago, hold a valid certificate issued by the Board of Examiners of the Chicago Public Schools which entitles the holder to teach in a specific area of responsibility

The various qualifying circumstances are explicated below.

Circumstances #1 — The Standard Special Certificate (Type 10) for Special Education areas will be issued to persons who hold a bachelors degree from a recognized college or university and meet general and professional education requirements. Special Certificates will be issued in the following areas:

(a) Educable mentally handicapped

(b) Learning disabilities

(c) Social/emotional disorders

(d) Trainable mentally handicapped

(e) Blind and partially seeing

(f) Deaf and hard of hearing

(g) Physically handicapped

(h) Speech and language impaired

Special Education Teachers employed to teach autistic children are usually certified in social/emotional disorders. Educational requirements for certification in that area are:

SOCIAL/EMOTIONAL DISORDERS

1. 32 semester hours including at least one (1) course in each of the following required areas:
   a. survey of exceptional children
   b. characteristics course in emotionally disturbed and/or socially maladjusted
   c. methods course in emotionally disturbed and/or socially maladjusted
   d. psychological diagnosis
   e. student teaching in emotionally disturbed and/or emotionally maladjusted
2. The remainder of the required 12 semester hours may be completed by taking additional courses in the above areas in other course work in special education.

Circumstance #2 requires that teachers hold a certificate for teaching in a regular classroom and have also completed the following course work.

a. survey of exceptional children

b. characteristics course in the area of special education

c. methods course in area of special education that the applicant wishes to teach

d. psychological and/or educational diagnosis

e. other course work in special education

Omitted is the requirement that there must be student teaching in the area of specialization such as emotionally disturbed or emotionally maladjusted.

Circumstances #3 includes the approval process for vocational certificates, substitute certificates, and general certificates for persons teaching adult education. The Provisional Certificate requirements most applicable to temporary approval for teaching in a special education classroom are:

(1) An individual must meet the requirements for a regular teaching certificate in another state and must present evidence of such.

(2) An individual must present certified evidence of having earned a bachelor's degree from a recognized institution of higher learning.

(3) The academic and professional courses offered as a basis of the provisional certificate must be courses approved by the State Board of Education in consultation with the State Teacher Certification Board.

A certificate earned under this plan is valid for two years and shall not be renewed.

Circumstances #4, the certificate validated by the Board of Examiners for persons teaching in Chicago is detailed in a handbook issued by the Chicago Board of Education, summarized as follows:

> Special Education teachers must first meet requirements for a teaching certificate. Certification in areas of exceptionally requires course work parallel to that required for state certification. In addition, introductory information stipulates non-academic requirements. For the Behavior Disordered teacher, the preliminary paragraph states:
>
> > Teachers interested in an assignment to this program must have a full understanding of child development and be able to work well with individuals as well as with groups, and to relate effectively to teachers, administrators, other school personnel, parents, and members of the community.

Staff Accreditation: Non-Public Schools The private agency programs, operating on a shoestring and dependent on volunteer staff, started with no tradition of professionally accredited staff. As tax dollars were transferred from the public educational system to the private, however, pressure began to build for the private agencies to meet stanards of personnel certification.

The definition of "trained staff" is an uncertain one at best. In legal terms, through the certification process, specified course content and a degree from a recognized university are the critical requirements. Empirically, the skills of a non-degreed person who has had substantial experience enhanced by appropriate inservice training may exceed the competency of recently graduated and legally certified teachers.

The Rules and Regulations for Approval of Non-Public Facilities Educating Handicapped Students (April, 1977 edition) allow for both levels of service personnel. Section 12.01.01 states:

> By September 1, 1977, at least twenty-five percent of the nonpublic facility professional staff who provide direct instructional services or who are directly involved in the development and implementation of instructional services, shall be composed of persons with a minimum of a bachelor's degree in one or more areas necessary to serve the handicapped student population, and who are State Certified in their field of competency.

The Rules and Regulations further state that professional support persons must meet licensing or certification requirements in their field of competency. Full time professional staff members holding a two-year degree from a community college or its equivalent in a child-related field or appropriate areas of handicapping conditions is counted as one-fourth of a staff member for purposes of counting certified staff (12.01.06).

Special Education administrative staff of public schools were asked during site visits whether, in their opinion, a particular discipline (speech therapist, psychologist, etc.) was most valuable in the classroom for autistic students. There was no agreement; most respondents stated that personal characteristics were more important than discipline background. However, several administrators stated spontaneously that the value of a well trained teacher's aide was at least equal to that of a certified professional.

A formal study, using Delphi technique, completed under the sponsorship of the Institute of Urban Studies at the University of Texas provides some pertinent information about levels of training in residential facilities (Suzan Roos, University of Texas). Nationally recognized experts were asked to submit predictions regarding, among other items, staff considerations over the next twenty years. Findings were that less trained professionals are expected to be primary deliverers of service and that professionals will serve as teachers or consultants to them.

This prediction bears some similarity to current policy defining the role of non-certified personnel. The **Rules and Regulations to Govern the Administration and Operation**

of Special Education state in Article XII, 12.07, that

> Necessary noncertified personnel employed in classes, programs or services in all areas of special education shall be under the direct supervision of a qualified specialist.

Further stipulations are that noncertified personnel shall be provided with inservice training experience "appropriate to the nature of their responsibilities," and that "inservice training shall be in lieu of the requirements for noncertified personnel set by the State Certification Board."

Non-Academic Preparation Teachers who were knowledgeable about developmental handicaps and effective remediation measures were asked about how they acquired their skills and information. Some had had summer employment in private agencies serving the severely behavior disordered. Some had worked in similar programs in other parts of the country. Many were self-taught having profited from extensive reading. Some teachers continue to seek out journal articles and continuing education opportunities to increase their knowledge. Substantive inservice training programs were usually judged as the most effective method for upgrading staff skills.

Some programs in Illinois have purchased staff training and program consultation from established programs in other parts of the country. Generally these programs function well during the initial years and as long as there is staff continuity. Problems may arise or programs deteriorate when the consultant contract is completed and there is no longer someone to turn to for help or when the originally trained staff terminates employment.

National Analysts, a Division of Booz, Allen and Hamilton, published in November, 1978, the results of a survey undertaken to determine the demand for externally supplied inservice training programs in the area of special education. Forty-four percent of 906 respondents indicated that they had programs for autistic children, but it is significant that the greatest need expressed for inservice training was the education of autistic children.

In light of the above findings, the certification requirements for special education teachers in Illinois merit close examination. Nationally, the issue of competency based teaching is attracting increasing attention. Most commonly, college students majoring in special education first encounter exceptional children in a classroom setting in their senior year. Observation of the classroom is the initial assignment followed by partial and perhaps eventual full participation in the classroom. The supervising teacher determines the extent of the student's responsibility.

The actual experience of managing a classroom of five autistic children five days a week is thus one for which most bachelor degreed teachers are woefully unprepared. A further consideration is that college students who have no actual experience in a special education classroom until their senior year are unrealistically delayed in finding out whether they have made the right choice of career.

Recommendations for remedying the problem include a vastly increased practicum component beginning in the freshman year and continuing in a variety of special education settings in subsequent years. (The value of experience with normal children for future special education teachers and vice versa should also be recognized.) Practica assignments designed to develop competencies in assessment, curriculum development, and curriculum implementation are recommended. Very specific competency evaluations by supervising teachers and appropriate faculty are also included in recommendations by national leaders in the field of special education.

The University of Illinois, Circle Campus, has for the past few years offered a unique graduate level seminar in autism. During the Spring quarter, students are enrolled in prescribed theory courses. Simultaneously they are assigned practica settings. Students who have already had classroom experience with autistic children fulfill the practicum requirement in a non-classroom setting, i.e., with the autistic child in his home, in a recreation setting, etc. Those lacking experience in the classroom are assigned to a class for autistic children.

Most students continue through the summer serving as staff at summer camps for developmentally disabled children. One week is spent at a summer camp for autistic children and their families.

Rutter (1978) states that "nothing short of living with such a child in an inpatient setting and taking care of him produces an awareness of the enormous wear and tear both physically and psychologically that occurs. . .and its reciprocal effort on the parent-child relationship." Participation in a course of study such as the one just described provides some understanding of the 24-hour responsibility for autistic children. Such experience is invaluable to teachers, not only in the classroom, but in their working partnership with parents.

In summary, the adequacy of preparation of special education teachers for autistic students is a highly individualized matter. The formal curricula offered in the universities or colleges are, with few exceptions, judged inadequate. The inservice training component lacks any consistency in content, interpretation, and implementation. How these defi-

ciencies affect the ability of families to keep their child in the community and how they ultimately affect the eventual degree of self-sufficiency of the autistic individual has not been evaluated.

V. **Costs** Essential to any planning effort is information about existing and future program costs. In the course of site visits, facility administrators were asked how much it cost to serve one autistic child per year. No reliable data was obtained.

In the first place, cost analysis is not based on uniform budget items. Non-public schools or private agencies, by the nature of their operation, must include usual overhead costs such as space, equipment, supplies, insurance, etc., in their budgeting procedure. Many of the public school personnel queried were uncertain of the cost of providing service to an autistic child and were aware only of personnel costs or those excess costs which are reimbursable under state or federal mechanisms.

Reported costs varied from $4,000 to $9,700 in the public schools and from $5,050 to $9,000 in the non-public facilities.

Summer term costs were from $400 to $650; again, these are of doubtful validity because they are not all-inclusive costs. Also, the varying length of summer programs contaminates the data.

Staff disciplines represented are also subject to wide variation. At one extreme, a special education teacher certified in emotionally disturbed with some help from a speech therapist is responsible for a classroom of five children. Under a different organizational structure, several classes for the handicapped share the services of certified teachers, aides, speech pathologists, psychologists, social workers, developmental therapists, and recreational therapists in a ratio of 1:2.

The composition of the classes themselves varies as to the severity of the handicaps and the ages of the children.

Nor are programs comparable in the ratio of staff to students which in the sites visited, ranges from 1:5 to 1:2. Educational levels range from bachelor to doctorate degrees with accompanying salary differentials. As a general rule, non-public schools reported higher staff to pupil ratios and lower staff salaries.

Physical Settings as a Cost Factor There is not sufficient information to draw any conclusions about physical locations as they contribute to overall program costs. However, in keeping with the thrust of current legislation, it would seem that there is little justification and equally strong contraindication for the erection of new special education buildings. New construction of itself increases the cost of providing education to chiidren with

exceptional characteristics and funds are better expended in improving the quality of educational programs.

VI. **Staff Ratio Considerations** Rules and Regulations of the Department of Specialized Education Services require that (Article IV, 4.04.2):

> Instructional programs which primarily serve children whose exceptional characteristics are either profound in degree or multiple in nature shall have a maximum enrollment of five (5) students.

Deviations from Article IV, 4.04.2 require approval from the Department of Specialized Educational Services. The possibility exists of increasing the number of students to ten with the addition of a qualified, non-certified assistant.

An optimal ratio of staff to children depends on many factors:

(a) Ages of the children
(b) Severity of their handicaps
(c) The individualized educational program
(d) Characteristics of the staff
(e) The intervention strategies required to meet the child's needs
(f) Physical setting

Ages of the Children and Severity of Their Handicaps: Younger children who are new to the educational process and have not learned to sit for five minutes or to pay attention for five minutes require staff time exceeding that necessary for children who have these behaviors established. Children who are not toilet trained or who do not feed or dress themselves also require richer staff ratios as do those children who have not acquired a means of communications.

A consistent problem in any class for autistic children is their very slow progress in undertaking or completing tasks independently. Evidence of this characteristic was apparent during the site visits. Individual activity in groups of three children, for instance, quickly fell apart as soon as the teacher transferred her attention to another student. In some of the older groups, an occasional individual student on a token system was completing an assignment with minimal attention from the teacher. But rarely did children in the primary grades show any ability to function without almost constant individual attention.

The Individualized Educational Program The IEP is theoretically based on accurate assessment of the individual child's strengths and weaknesses. It follows then that staffing patterns are affected by the IEP. For example, during any one day, a student may

be most appropriately learning in a one-to-one situation or in a one-to-three ratio. Goals that require physical therapy for their implementation may best be implemented in a group structure which is also addressing goals of socialization. Goals in speech therapy, on the other hand, may require a one-to-one staff ratio utilizing a speech therapist or may be best implemented in a group setting utilizing a music therapist.

VII. **Staff Characteristics** In order to accommodate the requirements of the IEP, the disciplines of speech education, occupational therapy, social work, psychology, music therapy, therapeutic recreation, nursing, psychiatry, pediatrics, and speech therapy may all be useful. No school system employs this total diversity of talent, nor is it necessary when alternate mechanisms for providing these evaluative and program activities are developed.

Germane to the issue is the number of staff. Current Illinois regulations which permit a ratio of one certified teacher to five severely and profoundly handicapped children is totally unrealistic. A teacher in these circumstances cannot even provide quality babysitting. If the teacher's education and experience are limited and meet only the minimum requirements for certification, the potential for disaster is even more profound.

A staff ratio of one adult to 2.5 children is minimal in a classroom of five autistic children. The additional assignment of time increments from disciplines such as psychology or speech therapy staff to the autistic class for regular periods of the school day, in addition to the services of a full-time certified teacher and teacher's assistant, would provide some progress toward a realistic staff/student ratio. The use of regular volunteers is also relevant to teacher/pupil ratios.

The development of a program of educational intervention for autistic children is limited by the fact that knowledge of both normal and abnormal development is seriously incomplete (Schopler & Reichler, 1976). No single profession has satisfactory knowledge of the processes of human development; nor does any individual have complete understanding of why development occurs within the parameters defined as normal. The limitation of knowledge regarding developmental deviations is equally circumscribed.

The emergence of specialized professions such as speech therapy, occupational therapy, and psychology, for example, have created some barriers to progress even as they have provided momentum to the search for knowledge. As separate disciplines emerge and gain recognition, the professional trained within a particular discipline tends to evaluate children from his unique perspective and to propose a program of remediation from a single perspective. A second consequence is that professionals are inclined to line

up behind their unique body of theory and to oppose differing viewpoints.

The disarray of the professions means that the child is sometimes evaluated and prescribed for according to professional bias. It also means that parents who are seeking help receive contradictory information. Already confused and frustrated by a child who does not make any sense to them, parents become more confused and frequently disenchanted with the professional persons whose opinions are in conflict.

Another aspect of specialization is that, as the training becomes more lengthy and expensive, the number of persons trained in the sub-specialty decreases. Also, the greater financial investment in the training is accompanied by a higher cost of purchasing the specialized service. Professionalism as a factor contributing to the high cost of providing services then acts as a deterrent to public support of specialized educational programs.

A further concern is that the disabled child needs to be seen as a whole, not in pieces. Despite the need for a careful evaluation of the child's hearing, vision, neurological status, and developmental skills, there must be a putting together of the various findings within the context of the family and the educational system in order to institute effective remediation. The role of generalist assumes particular importance if this synchronization is to take place.

Although each student's program should be based on his individual strengths and deficits, it is difficult to conceive of an individual education program for an autistic child which would not include goals related to communication, socialization, physical development and self skill development, as well as more traditional academic or pre-academic goals. To provide these educational services does not necessarily imply that a broad array of disciplines must be available for each child. The following paragraphs will discuss optional methods of providing necessary expertise.

The Chapel Hill Model at the University of North Carolina, Project TEACCH, provides diagnostic assessment and staff training for the state-wide system. It also provides educational programs for children residing in its geographic area. Eric Schopler of the Department of Psychiatry who directs Project TEACCH believes that if parents are to be successfully involved as collaborators in the treatment of their children, the staff must have a special quality of open-ness. He also believes that therapists who are **not** highly trained and skilled professionals are more successful in working with parents.

Each program in North Carolina is directed by an experienced Ph.D. clinical psychologist. The balance of the staff has diverse backgrounds, frequently not those of traditional disciplines. When a staff vacancy occurs, the position is advertised and written

inquiries requested. The first cut of applicants results from the written letters of application. The second cut follows personal interviews. The remaining three or four candidates are scheduled to spend time in a one-to-one situation with a child and separately with a parent while they are observed by existing staff. From these experiences, the applicant writes out his/her impressions and a planned intervention strategy. Upon completion of these tasks, the final assessment is made and the staff person selected.

The attributes sought are intelligence and creativity and a freedom from pre-conceived ideas or restrictions. The preference is to add to the staff persons who can bring enthusiasm to the job and who are mature in their understanding and acceptance of family diversity.

Although the senior staff represents the essential disciplines, there is an absence of hierarchal structure. Staff members learn from and consult with each other. Classified as psycho-educational therapists, they serve primarily as generalists, absorbing the skills needed for a variety of functions. The college community provides an unusual pool of potential staff members, which is not typically available. Yet TEACCH classrooms scattered throughout the state are able to attract staff and function similarly.

One advantage of this model is that the student's educational program maintains continuity of content and consistency of technique throughout the school day. All staff benefit from the specific area of expertise residing in any one staff member and incorporate goals in speech, for instance, into the pre-math component. Staff development is a natural and ongoing process, and the students profit from the broad range of abilities represented in the diverse staff backgrounds.

Autism educational programs in South Carolina are also not administered by the Department of Education. Autism is a separate line item in the state budget with funds allocated to the Department of Mental Health. Funds may not be co-mingled with the Department's regular budget allocation but are used to hire staff expertise in the field of autism. When, within a reasonable geographic area, a group of children is diagnosed as autistic, the assigned staff goes into the community to develop a program there. Local resources are identified and contracts written with them for specified services. As part of the contract, local staff must complete a training sequence at the central location. Programs are monitored and evaluated and contracts reviewed annually on a performance basis. The autism staff is also available as resource and consultant to established programs.

Diagnosis: Development of an appropriate curriculum requires an accurate assessment of the individual child. In turn, an accurate assessment is possible only when the assessment is performed by diagnostic personnel who are knowledgeable about a broad range of diagnostic instruments and who are aware of the problems peculiar to evaluating an autistic child. In the educational system, psychologists play a prominent role in the evaluation process.

Administrative and funding guidelines for special education services require documentation of the child's exceptional characteristics, including among the evidence, level of cognitive function. Autistic children, however, will respond both unevenly and inconsistently to examination using standard instruments. The reliability of test scores is questionable unless the psychological examination is conducted by a psychologist skilled in both administration and interpretation of testing instruments.

Current Illinois certification of school psychologists requires a master's degree from an institution of higher learning whose standards are approved by the State Board of Education; completion of a minimum of 56 hours of psychology, graduate or undergraduate level; and one year's supervised internship with school age children, preferably in a school setting and under a qualified supervising psychologist. Additional qualifications addressing specific competencies in diagnosis, data interpretation, etc. are also listed under requirements, but no method of measuring these competencies is stated.

Because autism is a low incidence handicap, the likelihood that a psychology intern will encounter a significant number, if any, of autistic children in the course of one year's supervised experience is most unlikely. That a school psychologist, upon completion of one year's internship, can serve as diagnostic resource or master strategist to the autism classroom teacher is therefore also questionable. To provide a reliable diagnostic profile; to prescribe remediation activities and techniques; and to continue as resource in the requisite ongoing diagnostic process demands extensive experience and specialized training beyond the minimum requirements for Illinois certification. A mechanism providing for continued or advanced education of school psychologists who evaluate autistic children would seem to be indicated.

VIII. **Assessment and Curriculum Planning Resources** Among the assessment instruments used in Illinois schools are the Bayley Scales; the Cattell; Denver Developmental; the Leiter; the Vineland; the Frostig; the Illinois Test of Psycholinguistic Abilities; the WISC; and the Stanford Binet. No preference for any testing instrument except as it is age-related was expressed.

The Psychoeducational Profile developed by Schopler at Chapel Hill incorporates three levels of evaluation: a skill or ability may be totally lacking, may be present, or may be classified as an emerging skill. The third category means that the child has partial knowledge of how to accomplish a task or may be able to achieve completion with help or demonstration. The emerging skills assessment is particularly valuable in giving direction to the teaching staff and in establishing realizable goals germane to the Individualized Educational Program.

The process of developing an Individualized Educational Program is well described in **The Illinois Primer on Individualized Education Program** (State Board of Education, Springfield, Illinois, 1979). Parental participation in developing the IEP and the methodology that will be used in implementing the IEP are particularly important when programs for autistic children are being developed. Parents' intimate knowledge of their children provides information critical to effective educational programs. The cooperation and active support of parents who feel that they have been treated honestly and respectfully during this process demonstrate the value of competent, confident, and open staff persons.

Curricula: Two social and legislative changes of recent history, de-institutionalization and the right of all children to a free and appropriate education, have been catalytic agents in instigating a search for teaching methods, materials, and curricula specific to the needs of school age autistic children. The dearth of materials prompted some public school systems to seek a means of filling the void.

Teaching Makes a Difference: A Guide for Developing Successful Classes for Autistic and Other Severely Handicapped Children was developed through funds provided to the California State Department of Education under Title VI B, Education of the Handicapped Act. The Santa Barbara County Autism Dissemination Project staff (Anne Donnellan, Lon D. Gossage, Gary La Vigna, Adriana Schuler, and Jan Traphagen) authored this two volume series composed of a teacher's manual and an administrative manual.

The Teacher's Manual is practical and specific. Chapter organization includes procedures for teaching new behaviors and reducing inappropriate behaviors; trial lesson plans; curriculum considerations; teaching communication skills. Sample forms for individual scheduling, data recording, informal assessment survey, student goals and objectives are included. This is a clearly presented and extremely useful guide for teachers of autistic children.

The Administrative Manual reviews relevant California legislation. It also includes information about setting up a classroom, core staff requirements, standards for program

planning, and sample content areas for curricula.

The two volumes are available from the National Society for Autistic Children, Suite 1017, 1234 Massachusetts Avenue, N.W., Washington, D.C., 20005. Incorporating the knowledge gained from several years of public classroom teaching, current research as it relates to the school age child, and the expertise of leaders in the field, these publications are valuable for both teachers and administrators.

One school system, Orange County School District of Orlando, Florida received funding under Title VI B of the Elementary and Secondary Education Act to develop and publish **An Educational Model For Autistic Children** (Orange County Public Schools, Department of Instructional Materials, 99 East Marks Street, Orlando, Florida, 32803). The four volume guide is organized as follows:

Volume I discusses the components of a public school program for autistic children; Florida's guidelines for identification and placement of the children; transition into other classrooms; and information about the physical environment, materials, and parent groups.

Volume II contains basic teaching procedures; behavioral management techniques; and a basic curriculum for autistic and seriously emotionally disturbed children.

Volume III contains further identification of children eligible for the program; staff development considerations; and a suggested training sequence for aides and volunteers.

Volume IV includes utilization of community resources; further discussion of staff development; speech, writing, and math curricula; a pre-vocational discussion and sequence.

Other helpful resources are: The National Society for Autistic Children publishes the **NSAC Communicator** which provides a forum for the exchange of practical ideas and explores issues germane to the teaching of autistic children.

The Teaching Research Infant and Child Center issues a series of monthly newsletters prepared by the staff of the exceptional child research program at Monmouth, Oregon (Teaching Research, Monmouth, Oregon, 97361). The information published is current and valuable to anyone associated with the field of developmental disabilities, including teachers of autistic children.

Utah State University (Logan, Utah, 84322) has educational packages useful to the classroom teacher of the severely/profoundly handicapped population. Dr. Alan Hofmeister is director of the Outreach and Development Division.

Dr. Robert Schalock has developed a systems model for teaching tasks to developmentally disabled persons which is both precise and sensitive (Dr. Robert Schalock, 522 East Sede Boulevard, P.O. Box 1146, Hastings, Nebraska).

The Division of Retardation, Department of Health and Rehabilitative Service in Florida developed, with Bureau of Education for the Handicapped funding, a media package which includes observation, intensive play, teacher made materials, development and trainability assessment, and parent involvement which would be helpful for inservice training (Resource Center, 1317 Winewood Boulevard, Building 2, Room 118, Tallahasee, Florida, 32301).

IX **Parental Involvement** Experienced and expert opinion emphasizes over and over again the importance of parental involvement in the education of autistic children. During the course of the study, parents, teachers, administrators, and other school personnel were asked about how parents were involved in their programs. The responses showed extremes of variation.

Public schools can encourage parents to participate in the child's education, but cannot require participation. Historically, many private programs have exercised the option to exclude autistic children whose parents did not participate in the educational process. Despite the philosophical validity of their policy, the results were punitive in that excluding the child from programs of potential remediation is more harmful than beneficial.

The autistic child's failure to generalize learning is one reason for encouraging family participation. Formal education absorbs only twenty-five hours per week. What takes place outside the school hours can accelerate the child's learning, diminish the child's learning, or subvert the educational endeavor. Hemsley's study involving experimental and control groups distinguished by parental and non-parental involvement demonstrated that behavioral and social improvement accelerated when parents were positively involved at home in a systematic endeavor to address problems of their autistic children (Hemsley et al, 1970).

Schopler (1976) appraises the question of parental involvement from the perspective of common sense and many years of experience. He recognizes that no two families are alike and that realistic expectations of their participation should reflect this diversity. He also gives consideration to the varying severity of each child's handicap as affecting educational outcome. His philosophical stance is that parents can contribute at least equally to the educational process; that a professional posture of hierarchal expertise does not encourage parental participation, but that a working partnership between equals

has the potential for exponentially multiplying progress.

In Illinois, there are schools where parents are encouraged to visit and to observe whenever they wish. There are schools that overtly or covertly discourage parents from involvement with the educational system. There are parents who visit frequently, participate in the child's program and are active supporters of the faculty and the program. There are other parents who are minimally involved and there are parents whose involvement is restricted to attacking the program and the faculty. There are parents who are not satisfied with the curricula or the methodology but are fearful of raising any questions.

The welfare of the child requires that school personnel welcome parents as equal partners in the educational process. It also requires that school systems adapt to parents' schedules and responsibilities by providing opportunities for parental involvement at flexible times and at flexible locations. School personnel also need to accept the limitations of parents and of themselves. Parents should discriminate between their legitimate efforts to improve educational programs and unrealistic expectations that may impede progress toward achievable goals.

Recognizing that the participation of parents in the child's education is beneficial has stimulated the development of books and manuals on parent training. Although the procedures are sound and well delineated, the usefulness of these texts for general application is questionable. They require parents to commit themselves to extensive periods of instructional time learning the procedures and language of clinical professionals. Teachers must devote an equal amount of time to preparing and conducting the classes.

There are assuredly parents who are candidates for this kind of participation and when there is a competent professional equally interested in devoting time to the endeavor, the results can be mutually beneficial.

More typically, parents, exhausted by coping with their child during non-school hours, resist this kind of demand. If teachers believe that "good" parents will willingly devote the time to study and to attend classes in behavior modification or operant conditioning, they are also likely to judge the parent who does not devote limitless hours to parent training programs as non-cooperative and not really interested in the child's welfare. Therefore, insistence on formalizing parent's instruction at this level of sophistication can boomerang and be detrimental to the parent/teacher partnership.

Parents do need to know how their actions and reactions encourage or discourage children's behavior. Home visits, classroom participation, and demonstrations can be used to achieve this goal. On a different level, public universities or junior colleges

respond to requests for community education and are appropriate vehicles for providing formalized instruction to both parents and teachers. But the quality and frequency of home/school communication as well as the degree of rapport between the teacher and parent are more likely to be crucial to the parent's commitment than a programmed text.

A variant to any of these approaches has been utilized in the state of Washington. Under a Bureau of Education for the Handicapped Grant, the Washington Society for Autistic Children collaborated with a clinical psychologist to provide parent training. Under the terms of the contract, groups of parents participated in the training programs. The trained parents then served as trainers for additional groups of parents in other locations.

In parent training, as in other aspects of the continuum of services, means of achieving goals should remain flexible and be predicated on the recognition that parents, teachers, organizations, and resources are all unique.

The purpose of education is to help children grow and develop, not to change parents. Irevitably parents do grow and develop from the experience of parenting itself. When educational personnel are patient and persistent and non-judgmental, they participate in a process of mutual growth to the benefit of the autistic child.

Relevant to the question of parent training is the problem of teacher burn out. When a capable teacher leaves, programs -- and children -- and families suffer. Teachers need understanding and support from parents and from administrators. They need to be in touch with other teachers of autistic children. They need time for more education, to get re-charged and re-stimulated. They need good diagnostic help so that their teaching is effective and rewarding. Failure to meet these needs accelerates the burn out process.

X **Parent Counseling** Although the degree of impairment among developmental components will vary with the individual child, the characteristic symptoms of autism become most prominent between the ages of 2½ and 5. By the time the autistic child is three years old, most parents have already been battered externally by the system and internally within the family as they experience the nightmare of life with an autistic child. Two problems must be addressed simultaneously: the behavior of the child and the devastation of the family.

No two autistic children are alike; it is equally true that no two families will react in the same way to the presence of a severely disabled child. Grief, guilt, anger, and marital stress resulting from the birth of a severely disabled child are increasingly being addressed in the literature or conference format. It is probably helpful for some part of

the population that names are given to the negative emotions parents experience. It is also possible that a new and artificial emotional system that fails to recognize each person's uniqueness is being promulgated to the detriment of the affected parties and that processing individuals through a prescribed emotional sequence can hardly be beneficial and may, on the contrary, set up another source of frustration.

To recognize, however, that parents of an autistic child are under a state of siege and that they are legitimately angry or resentful or exhausted or ambivalent in their feelings toward their child is to accord them the emotional rights of any human being. It is of crucial importance that the first contact within the educational system is with someone who is nonjudgmental, who is not threatened by justified or nonjustified attacks, and who is aware of his or her limited perspective and knowledge. Social workers or whoever is responsible for securing a developmental history need to be aware that often the very format of their inquiry is accusatory and that they unwittingly communicate an explicit message of professional superiority (Rutter, 1976).

The skill and competence of the first contact person are also extremely important. A knowledgeable professional has confidence in the ameliorative effects of a good educational program and imparts that confidence to the parent. On the other hand, a knowledgeable person also recognizes the unpredictability of any single autistic child's outcome and does not engage in questionable prognostications.

The competent professional is aware that effusive sympathy is nonproductive and wastes time that could be spent in addressing concrete problems. Educational programs should provide for the counseling and therapeutic needs of parents and other family members. However, the family itself should exercise control over its participation in traditional therapeutic work.

It is questionable whether it is within the province of the educational system to prescribe therapy or counseling as a routine component of the educational process. However, it is important that the educational system should provide or have as community resources competent and experienced staff and diverse therapeutic strategies appropriate to the expressed needs of individual family members.

Levels of therapeutic intervention should be available as follows:

(1) **Parent Groups:** Parent groups provide an opportunity to share common experiences and to decrease feelings of isolation. Parents may provide support for each other, may share successful strategies, may provide crisis telephone listening, may meet some social needs, may organize into advocacy groups, may serve as fund raisers

for program equipment, may utilize their meetings to increase their own knowledge of autism or of behavior management.

(2) **Group or Individual Therapy:** Parents of autistic children experience the same vicissitudes as other families. It also seems likely that the condition of unremitting stress may increase the family's vulnerability so that family members have a proportionately greater need for therapeutic resources than does the population at large.

(3) **Sibling Groups:** Siblings of autistic children may benefit from the opportunity to express their own discomfort and frustration. They may help each other by sharing their observations and their survival mechanisms.

(4) **Other Therapies:** The range of therapeutic options is infinite. For some families, library resources may be most useful whereas social/recreational opportunities may be beneficial for a different family. The therapeutic needs of any family will also change over time.

XI. PROBLEMS AND RECOMMENDATIONS

Problem: **Availability of Educational Programs** Identified programs for autistic children are unevenly distributed throughout the state. There are both metropolitan and rural areas where there are no public school programs for autistic children. Approximately 1,000 clasically autistic children in Illinois between the ages of 6 and 18 need educational programs to meet their unique needs. Approximately 4,400 in this same age group constitute a more broadly defined autistic population who require similar kinds of intervention. As nearly as can be determined about 250 children are being served in public school classes and another 50 in non-public school settings. No figures are available indicating the number of preschool or 18-21 year olds being served. Proposing a mechanism to assure that Illinois' autistic school age population is being provided an appropriate education requires addressing several problems: lack of diagnostic expertise; lack of trained staff; resistance of local education agencies to assuming financial costs which are probably higher than those of serving any other disability; confusion in policy and legislative mandates; the low prevalence in sparsely populated areas of the state.

Recommendations: (1) Inservice funds should be heavily allocated to training efforts in the field of autism.

(2) Resource teams should be developed as suggested elsewhere in this document.

(3) Local Special Education Administrators should be reminded of the PL 94-142 mandates relative to appropriate education.

(4) Parents should continue their efforts to make sure that their children are accurately diagnosed and that the Individualized Educational Program is appropriate to the child's needs.

Problem: **Services in Sparsely Populated Areas** Because of the small number of children requiring specialized educational services in these areas, providing services to autistic children in rural areas poses particular problems.

Recommendations: (1) The Autistic Service Center as proposed in the Autism Study should include boarding school models and establish curriculum and program consultation resources to meet the needs of sparsely populated areas in Illinois.

(2) Joint agreements should address the financial and service delivery demands of the severe/profound population in the context of efficient and equitable distribution of responsibility.

Problem: **Educational Programs** Procedures for educating children with various disabilities have become increasingly specific through years of experience. However, this is only partially true as far as autistic children are concerned.

Although an increasing number of published studies describe effective intervention methods, many articles describe success with a single individual. Because of the search for successful strategies, many persons indiscriminately apply a published procedure to other children; the technique successful with one child may not only be useless with another child, but may exacerbate the symptomatology.

Recommendations: (1) Programs that are well structured and based on behavioral principles have generally been most successful. However, without goal evaluation, slavish adherence to any single management system can lead to disappointing results. Ingenuity, sensitivity and practical common sense are all necessary to achieve maximum results.

(2) The likelihood of successful remediation is magnified if there is a working partnership between home and school. Such partnership requires frequent communication, mutual support rather than destructive criticism, acceptance of the human limitations of both professionals and parents.

(3) Ratio of staff to students will exceed those required in other specialized educational programs; for example, 3 staff to 5 students rather than 1 staff to 5 students is a recommended staff/pupil ratio.

(4) Different kinds of staff specializations are necessary and should be available at least for resource and consultation.

Problem: **Professional Training** Illinois has no formalized mechanism for meeting the needs which exist relative to preparation of staff of current or proposed autism programs in the educational area, the residential area, the vocational area, or the family support area.

Recommendations: (1) In concert with activities toward development of residential programs, the need for staff training should be addressed. Two residential programs in the state should be located (one north and one south) where an affiliation with a university is possible and where an affiliation with a medical institution is possible.

(2) Residential programs from inception should build in a training site component.

(3) Curricula, materials, and program development for the state-wide system should be included in the north and south residential facilities.

(4) Mobile training teams representing the various disciplines should be developed as a component of these same centers.

(5) Concurrently, the Department of Specialized Educational Services of the Illinois Office of Education should begin developing certification requirements explicating the specific credentials for teachers of autistic children.

Problem: **Diagnostic Evaluation** Knowledge of diagnostic procedures and the level of diagnostic expertise necessary to planning an educational program for autistic children are minimally available in Illinois.

Recommendations: (1) The preparation of school psychologists should require extensive knowledge of autistic characteristics affecting diagnostic formulation. Inservice training funds could be utilized to purchase consultation designed to improve diagnostic skills.

(2) School psychologists should be trained in the particular use of non-verbal testing instruments in evaluating children who display autistic characteristics.

(3) Comprehension and performance generally vary widely from one day to the next so single session evaluations are unreliable. Therefore an extended and ongoing diagnostic process is necessary to adequately evaluate an autistic child. A multiaxial evaluation is useful with autistic children. For instance, speech competency on the nine-month level, motor skills coordination on the three-year level, and social/affective skills on a two month level are developmental discrepancies typical of the autistic child.

(4) Time must be spent getting to know the family, the particular problems they are facing, their attempts at remediation, and in gaining a realistic picture of how much involvement can be expected from family members.

Problem: **Pre-Vocational Education** Studies relative to on-the-job performance of developmentally disabled persons show that social behaviors and relationships are highly correlated with failure or success (Schalock, 1978). For the autistic person whose social skills are severely impaired, pre-vocational training is minimally available.

Recommendations: (1) Inservice training as well as state conferences and workshops should stress the importance of pre-vocational training that addresses the particular deficits of the autistic student.

(2) Within these same formats, there should be training relative to utilizing the characteristics of the disability, i.e., perseverance, rote memorizaton, etc., as preludes to vocational training.

(3) Pre-vocational materials for the developmentally disabled should be adapted to meet the unique learning styles of the autistic child.

(4) Higher functioning autistic children should not be directed to occupations below their capacity, but should have the kinds of education and training that are commensurate with their ability.

Problem: **Vocational Training** There are more late adolescent autistic persons in the community than there were even a few years ago. As yet, the vocational needs of the late adolescent or young adult have not been addressed separately within the educational system. Rather, existing sheltered workshops have been the primary vocational resource although current staffs of the workshops are not trained in the characteristics of the disability.

Recommendations: (1) Before any vocational placement is made, the individual student should be re-evaluated by a person knowledgeable about the autistic syndrome.

(2) In order to accomodate the range of abilities within the autistic population, a broader range of occupations should be available than those of the typical sheltered work environment.

(3) Residential facilities should provide vocational training on a broad continuum. The low functioning autistic person can perform some work assignments if a persistent, long term effort is made. For higher functioning autistic persons, the goal should be preparation for regular employment and independent living.

Problem: **Academic Preparation** There is no consistent provision in Illinois' higher education system for developing professional expertise in the field of autism.

Recommendations: (1) University Departments of Special Education, Psychology and Social Work should develop curricula content for specific courses in autism.

(2) Practica components in these disciplines should be structured to provide experience with autistic children in non-academic settings as well as in school settings.

(3) The required practica components should be increased so that both quantitatively and qualitatively the autistic course sequence is adequate.

(4) Extramural courses as well as on-site courses in autism should be made available.

Problem: **Consultation Resources** In order to develop programs and train staff, public and non-public school systems currently have no option to purchasing out-of-state consultation.

Recommendations: (1) Illinois through a joint venture of the Department of Mental Health/Developmental Disabilities and the Department of Specialized Educational Services of the Illinois Office of Education should develop its own resources for program development and staff training.

(2) The Autism Service Center as proposed subsequently in this document should be studied as a means of filling the current vacuum in diagnostic expertise, training sequences, materials development and general resource for autistic programs across state agencies.

(3) Many of the recommendations made elsewhere in this document are related to the broad provision of educational services to the population at need. The Autism Advisory Council has expressed its interest in continuing in the implementation phase of the study and should continue to recommend actions toward assuring an appropriate educational programs for Illinois' autistic children.

Problem: **Lack of current information about autism in academic sequences** Review of a limited number of college texts in special education and speech and hearing disorders reveals that information about autism is neglected or out-dated.

Recommendations: (1) The Department of Specialized Educational Services, Illinois Office of Education, should address with appropriate academic faculty the need to supplement textbook context with current literature and research findings in the field of autism.

(2) The Department of Specialized Educational Services, Illinois Office of Education, should include presentations about the diagnosis of autism in the conferences or workshops they sponsor.

(3) Inservice training for Child Find personnel should include diagnostic information about autism.

Problem: **Parental Involvement** The role of parents in the education of autistic children is variously interpreted to the detriment of the educational process.

Recommendations: (1) Academic preparation of staff persons employed in autism programs should include course content in the impact of catastrophic illness on the family.

(2) Academic preparation should include theoretical and experiential components in establishing parent/school partnerships.

(3) Consultation and therapeutic/support resources should be available to staff persons employed in autism programs as well as to families of autistic children.

(4) A variety of community resources should be mobilized to provide an array of training opportunities for both professionals and parents.

Problem: **Barriers to Parental Participation** The physical and psychological environments in which autistic programs take place frequently discourage parental participation in the autistic child's educational program.

Recommendations: (1) Programs should be located in facilities and locations that encourage both formal and informal parent observation and participation.

(2) All information about the autistic child's program, problems and progress, and the staff's management techniques should be shared with the parents. No aversive therapy should be undertaken without the full knowledge and understanding of the parents.

(3) Group process or an analogous process should be instituted early in the school year so that barriers to staff/parent communication may be reduced. Direct service staff, administrative staff, parents, and consultants should all participate.

Problem: **Family Support Systems** Families of autistic children and adults are subjected to unusual and severe stress because of the nature of the disability. They also cannot fully participate in the ordinary and expected social or economic processes of society because necessary support systems such as trained baby sitters, trained homemakers, extended day care and respite care resources are not available. Mothers, for instance, cannot usually work outside the home and if faced by economic necessity to do so, must institutionalize the child.

Recommendation: The Governor's Planning Council on Developmental Disabilities and the Illinois Society for Autistic Persons should take the leadership

in activating those existing legislative mechanisms which can provide a solution to this problem. Legislation germane to this issue is contained in the Appendix to the Autism Study.

Problem: **Lack of leisure/recreation opportunities** In some Parks and Recreation Districts there are after-school or summer programs for handicapped persons. In some areas, the consumer pays partial costs of the programs up to $100.00 per month—which eliminates many potential participants.

Recommendations: (1) Parents should determine what recreational opportunities exist in their area.

(2) Parents should meet with local parks and recreation boards to discuss their needs, including financial costs of existing programs. (Under 504 legislation, handicapped persons must be provided recreational services just as non-handicapped persons are.)

(3) Community education (promoting utilization of school buildings during non-school hours by the community) should be studied by the Illinois Association for Autistic Citizens to ascertain its potential for leisure/recreation and after school hours programming.

RESIDENTIAL PROGRAMS

> The range of behaviors which may threaten [the autistic child's] family life is quite wide. These include temper tantrums, messy eating habits, special food preferences, poor toileting habits such as urinating in heat vents, and an inability to stay out of sibling's property. Only the life style the family is trying to build or maintain can define these adaptability problems. (Wing, 1976, p. 231)

I. **Need For Residential Programs** All autistic children will eventually live away from home. The separation may occur at age 10, or 15 or 20, or 45. It is, in any case, not a question of whether this will take place, but only of when it will happen.

There are several reasons substantiating the need for residential options available from early childhood on through adulthood.

(1) The younger child may need some form of residential care simply because the family cannot survive living with the disability. During a recent conference, one of the country's leading experts on residential care, Amy Lettick, herself a parent, discussed the need for residential options. She stated that ten years ago, most autistic children disappeared into institutions for the mentally ill or the mentally retarded, and the families did pretty well. Now most children and young adolescents are remaining at home and the families are **not** doing well. Brothers and sisters, mothers and fathers are experiencing increased rates of emotional disturbance as a result of the family complications and stresses occasioned by the presence of an autistic child. Broken marriages are one result of the unremitting burden of an autistic child and when there is a divorce usually the mother then has the sole responsibility of caring for the child.

The family of an autistic child is assuredly vulnerable to the pressures which sometimes culminate in child abuse. Public knowledge of abuse of handicapped children in general is just beginning to emerge, and the number of cases of abused autistic children is difficult to assess. Contributing to the difficulties of determining whether there is abuse is the fact that these are children who are frequently nonverbal and as self-injurious children may be responsible for their own bruises. They also may lack the ability to protect themselves from the abuse they receive from other children--sometimes their siblings.

Conversely, some autistic children are aggressive and prey on younger children in the family. They are typically insensitive to other people's pain and

lack the empathy that normally serves as an inhibitor to unrestrained violence. Such children may improve sufficiently after a period of time in an effective residential setting so that they can return home on either a permanent or part-time basis.

(2) As autistic children become older, their need for residential care may increase because their physical size creates management problems. Parents may become fearful of living with an aggressive autistic adolescent whose judgment is unreliable.

(3) Some skills may be taught more successfully outside a family setting. Salaried personnel may be more consistent and more persistent in making legitimate demands of autistic children and adults.

(4) Parents may be able to maintain the child in the family longer if there are times when they can be home without him/her. The availability of time by themselves or of time with their other children may be the critical factor in decisions parents make relative to institutionalization.

(5) In the interests of normalization, at the same time that normal children leave home, i.e., in late adolescence or early adulthood, the autistic child should make the separation from home.

(6) Illness, death, divorce and similar crises may require placement of an autistic person outside the home.

Although there is no cure for autism, the technology exists now to modify the disturbing behaviors characteristic of the syndrome and to increase the functional level of persons afflicted with the handicap. Typically, practice lags behind knowledge. In a vast human service system such as Illinois', the difficulties of disseminating up-to-date information and secondly, of ensuring that philosophy and practice keep abreast of current developments are enormous. When a developing body of knowledge impacts upon the service system of more than one state code department, difficulties are compounded.

Community based services for autistic persons are relatively recent and research about the effects of intervention are therefore just emerging. Follow-up studies of autistic individuals who have been diagnosed and provided treatment during the school age years, indicate that without continued specific programming into and throughout adulthood, progress ceases and regression is likely to set in. This is consistent with the nature of the handicap. The child's difficulty in generalizing learning would suggest that the mechanisms for retention and retrieval of information are either absent or malfunctional. That the painfully acquired skills are lost when the necessary environmental stimuli are

absent (as for instance, in a typical institutional setting) is a further manifestation of the same characteristic and primary deficit.

The implications are that the cost and effort of educating autistic children is wasted unless the educational component is part of a planned continuum of services. In short, the absurdity of such investment as is required by PL 94-142 becomes apparent unless vocational and residential services are in place as logical sequels to mandated educational services.

Currently, approximately 97% of all autistic individuals are eventually institutionalized. However, nowhere in Illinois' state operated institutional system are there specific programs for autistic children or adults. In other parts of the country, there are residential programs effective in stimulating and maintaining a desirable level of function in autistic children and adults. The political/economic decision of whether Illinois will utilize knowledge useful to this end has yet to be made.

II. **Relevant Issues** The myth has already been exploded that deinstitutionalization of itself means reduced costs, i.e., reduced taxes. Equally spurious claims that a community based comprehensive continuum of services for autistic persons will automatically result in a reduction of public expenditures do not merit serious consideration.

It is not that a sound case cannot be developed establishing long-term cost/benefits; Short-term, however, costs are likely to increase. But the contingencies within the system that preclude a short-term cost reduction are not related to services to autistic persons per se, but rather to those that are operative throughout the economy.

(1) Costs of any public or private endeavor have escalated and will continue to escalate as a result of inflation. The increasing costs of salaries, heat, maintenance, food, medicine, typewriters, and paper all contribute to the increased operating expenses of institutions, group homes, or whatever.

(2) The largest industry in the country is the public employee sector. Like other industrial groups, it seeks to protect its share of the market, to enlarge its share of the market, to increase the wages and benefits of its members, and to increase the scope of its operations. In many communities, the public institution is a vital and perhaps the major factor in the local economy. In the interest of self protection, public employees tend to encourage those practices which ensure their continued employment and to discourage those solutions which will render their services superfluous.

(3) The legitimate claim is made that, although institution populations have

decreased while staff numbers remained constant, the enriched staff ratios do no more than bring institutions into compliance with recommended standards. However, there is no evidence that the improved staff ratios have so far been significant to long-term improvement in the patient population. It is policy and chemotherapy rather than process which has made the more recent inroads on patient census figures. There is, for instance, no information about retraining programs for employees who have been reassigned as a result of patient population shifts. More of the same does not equate with improved quality of care. One of the reasons that the investment required short-term will be higher, not lower, is that training of personnel, hiring sufficient numbers of personnel, as well as planning and implementing the necessary continuum of services will add to immediate costs.

(4) An additional factor contributing to increased costs in the immediate future is related to the distribution of money. Compliance with PL 94-142 increases the responsibilities and thereby the costs of the educational system. For those children who do not meet the criteria of other agencies and who by reason of the severity of their handicap cannot be educated in the community, the costs of residential care must now be borne by the educational system. The number of children placed in residential care is not increasing; therefore, in theory, the total expense should not be remarkably inflated. Simplistically it would appear that those agencies who prior to the advent of PL 94-142 had the responsibility of providing room and board and of supplementing tuition costs should now experience a reduction in their budgetary requirements and that the savings realized should be transferred to the educational system which is now mandated to provide these services.

However, the current interagency financial squeeze is a veritable re-run of the move from institutional to community based services for the mentally ill. The exodus from the institutions has been accompanied by an increase, not a decrease, in institutional budgets as well as by an increase in the community agencies' budgets. The same situation prevails as the educational system begins to share in the cost of residential care.

Existing political, economic and social forces militate against any redistribution of money. Economically it may mean a loss of jobs; politically it means a powerful constituency marshalled to defeat any candidate for public office who supports a decrease in agency expenditures; socially it is interpreted as a failure to support services impinging on the quality of life.

(5) An important consideration is that especially as regards services to mentally ill children, funding has never been adequate. For example, the FY '79 appropriation to purchase care for mentally ill children in a residential setting (Individual Care Grant Program) was exhausted when the fiscal year was only half over. The FY '80 appropriation will suffice only to take care of children who are on a waiting list; in essence, this means that there will be no mental health money available during the new year for children whose needs are not already established. Obviously there is no surplus of money in this category to be transferred to the educational system.

The earlier infatuation with short-term intensive treatment of mental illness did not address the needs of children with a chronic, unremitting illness. A current priority, to return to Illinois children who have lived for many years outside the state, means that autistic children will be returned to a system that has made no provision for them. Also, parents who are now for the first time seeking placement for their children have no Illinois resources.

III. **Levels of Residential Care** The era of the individual's consignment to a maintenance institution for his expected lifetime is over. It is neither economically nor socially acceptable. It is also true that residential care is no longer a one-dimensional concept. It is only when levels of residential care are established that are relevant and adaptable to unique needs, that the benefits can be realized. The same problems that plague the medical system can skyrocket residential costs. For example, providing a uniform highly cost intensive accommodation for every patient in a hospital has contributed to excessive medical costs. The same trap has been characteristic of the social service system. The only alternative to family care has been institutionalization whereas a multi-level system of residential options would utilize institutionalization only as a last resort.

1. **Respite Care**

The health system is reducing the number of hospital days and achieving some cost reduction by utilizing outpatient surgery; similarly, institutionalization of the autistic person can be avoided or deferred if necessary support services, external to to the traditional residential placement system, are available in the community. One support service vital to the above goal is respite care of sufficient quality and quantity to meet varying needs.

A. Emergency or crisis care is necessary when a family faces unexpected illness or temporary disability. Friends or relatives or babysitters can usually provide help on a

stop-gap basis for the family who has normal children or adult offspring living at home.

These resources are not available to families who harbor autistic children or adults. Neither relatives nor friends feel capable of taking on the responsibility, especially for a child who is likely to be even more difficult in the midst of change.

One solution is to develop a corps of trained babysitters and to make sure that the babysitter spends time with the family when there is no emergency.

Another solution is to have residential beds available and to have a staff trained in the exigencies of autistic behavior.

B. Respite care also needs to be available on a regular basis so that families have opportunities to live like other families. The kinds of activities and experiences taken for granted by most families are denied the families who have an autistic child or adult in their midst. Shopping, relaxing at home, visiting with friends -- all the ordinary and undramatic activities that are implicit in normal family living are colored by the constant presence of the autistic child.

C. In the course of this study, many parents were asked what would make a difference in their lives. A particularly poignant and frequently expressed need is exemplified in the following comment: "I wish Elizabeth had a friend, someone to go to the park with, to maybe play out-of-doors with. I am constantly with her and she is with me."

One meaning of respite care is paid companionship so that families have some relief. Therefore, trained workers who come into the home for a few hours or for a weekend is another level of respite care.

D. Beds available over the weekend in a residential setting can also provide respite care.

E. Recreational programs after school and on Saturdays are another way of providing relief for the family.

F. Summer camps for autistic children are needed so that families can vacation like other families.

G. Another facet of respite care is the opportunity for families to vacation together.

One well designed program is now available in Illinois for one week each summer. The attractive location is on the George Williams Campus at Lake Geneva. The program options available to the participants are diverse. At one end of the spectrum, parents may sit and rock on the porches of their cabins if they wish or -- at the other end of the spectrum -- participate in all the programs planned for them

such as sailing, antiqueing or an evening at the Playboy Club. Siblings may attend a day camp staffed by George Williams College students. Interns from the autism seminar at the University of Illinois provide activities for the autistic children from seven in the morning on through the evening as babysitters. Families can be together or apart as they wish in any combination and at any time of day.

Free of the constant care of the autistic child, the parents can enjoy the companionship of each other and of other adults. The staff learns from the experience of 24-hour exposure to the children and their families. And the autistic children thrive in this atmosphere. The negative aspect of the program is that it is available only one week during the summer and at only one location.

2. **Foster Care**

One avenue of providing residential care is the development of training homes, foster homes where the surrogate parents have completed a professionally administered course in behavior management and continue to receive direction and supervision in their job. The salary must be sufficiently competitive so that the necessary caliber of foster parent can be recruited. A concomitant requirement is sensitive supervisory staff who can work with the natural parents so that they can accept the placement, retain their involvement with the child, and utilize the interim to enhance their own capabilities.

Regular foster homes that are available for both respite and semi--permanent care must also include a training module for the parent substitutes. Supervising staff for all foster homes should be in frequent contact -- at least monthly -- and should make available a crisis number so that foster families have the support necessary to maintain their roles.

3. **Permanent Residential Placement**

In the 1970's the small group home is acclaimed as the most desirable form of residential care. In reaction to the inhumanity and neglect of the dismal institutions where the developmentally disabled population was warehoused mid-century, the pendulum has swung to the other extreme. To many families and professionals, the small group home has become the only acceptable alternative. There are several reasons for its attraction -- among them the term itself. **Home** sounds better. It promotes the illusion that limited numbers of non-related persons living together by reasons of a handicapping condition are not, in fact, living in one form of institution.

Planning for long-term residential care requires an examination of the benefits and

the detriments of differing physical accomodations.

Small group homes are advantageous in that they approximate a normal living environment. Accommodating six or less residents, they resemble a large-size family home rather than an institution for disabled persons. Transportation, movies, stores and other natural community resources are more readily available. Staff is more readily attracted to a work environment that is non-institutional and more readily accessible to their homes. Families may maintain closer contact when distances are reasonable and emotional ties are not weakened by reaction to institutional separation. Preliminary reports indicate that even profoundly afflicted individuals make exciting progress in small group homes.

The disadvantages are related to the lengthy process of purchasing or building suitable dwellings when there are immediate and pressing needs. Preparing and processing grants for financial support requires months and sometimes years of effort. Securing other necessary financial support entails extensive time commitments of both volunteers and professionals. Problems of zoning are almost always a consideration. A potential danger is that infatuation with this one model may ignore other options equally desirable and in some instances more appropriate.

Utilizing existing public facilities obviates some of the above problems. There is physical space available. There is financial support in the institutional budgets. There are no zoning problems.

On the other hand, other problems relative to utilizing already existing facilities are numerous. Living in an institution teaches adaptation to institutions, not to normal community living. Finances and personnel may be subject to political manipulation. Custodial care rather than a program of active therapeutic intervention is likely.

However, if the factors most critical to maintaining skills already acquired by the individual and to developing additional skills are those of program philosophy, program content and staff composition, and if the physical setting itself is of secondary importance, careful use of existing facilities could address the need for residential care, with some degree of expediency.

IV. PROBLEMS AND RECOMMENDATIONS

Problem: **Residential Services** There are for all practical purposes no residential programs for Illinois' autistic citizens.

Recommendations: (1) Development of residential programs including foster home care, respite care, transitional care, and permanent care should be the first priority activity for the ensuing year.

(2) A state-wide committee on residential services should be formed. In the interests of expediency and to ameliorate the problems of travel, the committee should be divided into a Northern District sub-committee and a Southern District sub-committee, each one addressing the unique needs of its area, but maintaining close communication and meeting together as indicated.

(3) The Department of Mental Health/Developmental Disabilities, the Illinois Office of Education, the Department of Rehabilitation Services, the Illinois Society for Autistic Children and the Governor's Planning Council on Developmental Disabilities should be included in all residential planning efforts.

(4) Any move toward providing residential care in existing state institutions would require as a minimum that:

(a) Available institutional space should be separated into small operational units housing not more than six residents.

(b) Typical institutional components such as bathrooms and kitchens should be modified. Each living unit should have a kitchen, laundry equipment, and normal bathroom facilities.

(c) Current restrictions relative to resident employment should be legislatively changed. Autistic persons need to cook, to make beds, and to cut grass as part of their therapeutic program designed to promote normalization.

(d) Funding should be adequate to assure sufficient numbers of competent staff.

(e) Governance models should be set up for evaluative purposes:

I. Contract with a community not-for-profit agency for operation

II. Contract with a for-profit organization for operation

III. Contract with a parent group for operation

IV. Continuation as a state-operated facility.

(f) A state board to oversee and monitor any of the models should be legally authorized and a professional advisory group should be established to serve as resource to the residential programs and to the state board of directors.

(5) The Autism Service Center concept should be evaluated and developed as a possible means to addressing residential and other service gaps.

AUTISM SERVICE CENTER CONCEPT

I. **Rationale:** When the Governor's Planning Council on Developmental Disabilities and the Department of Specialized Educational Services of the Illinois Office of Education jointly sponsored a study of autism, the ultimate goal was to develop a comprehensive continuum of services for Illinois' autistic citizens. To provide the sound structure necessary to implement such a service continuum requires: addressing identified gaps or deficits, and establishing a mechanism for assuring continued excellence of the system. The "Service Center" is proposed as a means of addressing some deficits in the system, and will be discussed first in relation to each of the perceived deficits.

1. **Lack of diagnostic expertise**

The service center would provide training for physicians, nurses, psychologists, social workers, and special education personnel. Normal academic preparation for any of these disciplines requires completion of a curriculum specific to the particular profession. These standard curricula, when they do include the syndrome of autism, may broach it on a superficial level; even the minimal information provided may be inaccurate or out-dated. Therefore, assurance that these professional persons will be cognizant of the disability, knowledgeable about specific symptomatology, and capable of making a differential diagnosis requires both substantial theoretical knowledge and experiential training. An Autism Service Center staffed by experts in the field and providing a continuum of direct services to an autistic population will provide an effective arena in which to develop diagnostic expertise.

Because Illinois has not provided the kinds of education that develop diagnostic expertise, both under and over-diagnosis may occur. Not only are children afflicted with autism not recognized, but children may be diagnosed as autistic when, in reality, their symptomatology results from a different condition which requires medical intervention or a specific education program.

Development of diagnostic expertise is particularly vital in order to begin a comprehensive program as nearly as possible. The present institutionalization rate may begin to decrease when there is early recognition, early treatment, and early and appropriate education.

It is also important that each one of these disciplines understands the function and contribution of the others. An Autism Service Center will provide a simultaneous training experience that will encourage future effective diagnostic team operation.

2. **Lack of trained personnel for direct service.**

A consistent finding of the study has been the dearth of adequately trained personnel at all levels. The Autism Service Center will provide training modules for special education administrators, special education teachers, teachers' aides, communication specialists, recreation specialists, music therapists, psychologists, and social workers. Both theoretical and practical training is immediately necessary to increase the supply of trained staff to provide service in a variety of program settings. Trained personnel are needed in public and private educational programs, in parks and recreation departments, in sheltered workshops, in community mental health centers, and in residential living centers.

3. **Lack of Resource Staff**

A frequent request from operating facilities is for some central source which would provide information as well as personnel to go into the field to help with implementation of new programs and provide consultation to existing programs. The proposed Service Center would be the base for a field service corps which will address these identified needs. Locating the Autism Resource Teams at the Center will provide a natural avenue for maintaining communications. The resulting cross fertilization occurring between components of the system would be a further benefit accruing from the proposed Center and its functions.

4. **Lack of minimal resources for development of curriculum and materials**

Because commercially developed teaching materials are rarely useful with the autistic population, staff frequently spend many hours developing their own methods and materials to address the autistic child's needs. Furthermore, autistic students are voracious consumers of materials. Not only do they need a wide variety of materials, but because each child possesses different characteristics and develops at his own individual rate, the need for a multiplicity of resources is especially acute.

The Autism Service Center will have as one of its objectives the development and testing of useful materials and ideas, and the dissemination of same. It will serve as the state's resource for these program essentials.

5. **Lack of residential resources**

Illinois, for all practical purposes, has no residential facilities for autistic patients. If the needs of the population are to be adequately addressed, a variety of residential options must be available. The Autism Center will be a first step toward meeting the need for residential placement as follows:

1. In sparsely populated areas of the state, the limited numbers of autistic children and

their separation by geographic distance combine to make effective and efficient community programming difficult. A viable alternative is participation in a full 24 hour program during the week, and return to their homes for weekends and vacations.

2. Some children may need a residential placement as they reach adolescence or pre-adolescence when behavior problems may become more acute. These students could utilize the Boarding School model on a flexible basis, in part to give their families some immediate relief. Additionally, utilizing a 24 hour setting for re-evaluating and re-designing a program of behavior control may result in the family's being able to keep the child at home.
   a. Respite care: The need for respite care resources is discussed in the chapter on residential care.
   b. Extended diagnostic: A period of residential care may be the only recourse when families and community based programs are at an impasse in their efforts to evaluate and prescribe for particularly difficult symptoms. Twenty-four hour evaluation and attempted remediation techniques over a period of weeks may be necessary prior to return to the community.
   c. Transitional care: A limited residential stay to establish skills necessary for independent living may be necessary for young adults.
   d. Long term residential care: Realistic planning requires recognizing the need for permanent residential placement for a proportion of the autistic population.

SAMPLE BUDGET

Provision of psycho-educational
program for five autistic children
in public or private setting

COST ANALYSIS: ONE CLASS FOR FIVE AUTISTIC CHILDREN

Personnel	Base Salary	Regular School Day % Time	Regular School Day Cost	Extended School Day % Time	Extended School Day Cost
Certified teacher (1)	$14,000	100	$14,000		
Trained aide (1)	6,500	100	6,500	50 x 2	$ 6,500
Communications Specialist (Individual sessions, planning, inservice training and staff consultations: 8 hours per week)	15,000	20	3,000		
Other Therapist (Direct Service, consultation, and inservice training for a total of 10 hours per week) See budget narrative for position justification.	12,000	25	3,000	25	3,000
Social Worker	14,000	25	3,500	75	10,500
Psychologist	14,000	10	1,400		
Medical/Psychiatric Consultation- 2 hours per week @ $50 per hour			4,000		
Administration (4 hours per week)	23,000	10	2,300		
Secretarial support	8,400	10	840		
			$38,540		$20,000
	Fringes @ 18% (base $35,980)		6,217		3,600
	Sub-total, personnel costs		$44,757		$23,600
Other Costs					
Space and utilities (Room 30 x 20 = 600 @ $7.00 per sq. ft.)			4,200		
Classroom materials (5 x $50)			250		250
Equipment			500		500
Food (lunch @ 5 x 5 x $ .75 x 40 weeks)			750	(snacks)	250
Transportation* (5 x $1,000)			5,000		
Sub-total			$10,700		$ 1,000
Total program cost			$55,457		$24,600
Per pupil cost			**$11,091**		$ 4,920
Cost of regular plus extended school day			$80,057		
Per pupil cost			$16,011		

Costs do not include room adaptation such as carpeting, time out space, gymnasium, fence for playground, playground equipment, etc.

*Total handicapped transportation (State of Illinois) estimated at $55 million for 44,000 children or $1250 per child. Autistic reduced because of not needing adaptive equipment such as lifts on buses.

NARRATIVE TO SUPPORT BUDGET

The sample budget represents as far as possible typical costs of providing an educational program for 5 autistic children. Obviously, no budget will reflect the actual cost variance among communities purchasing the same or similar services or goods. This is particularly true in respect to personnel costs. For instance, private agency directors who serve on the Advisory Council state that the salary levels of their employees are usually well below those used in this budget.

Extending the school day by 2-3 hours permits mothers to work outside the home; provides a form of respite care; increases the number of hours of consistent management of the autistic child; provides time for leisure/recreation activities; provides time for social experiences in the community. Sources other than the eduational system—such as the Department of Mental Health/Developmental Disabilities—should assume financial responsibility for the added costs of extended program hours.

The budget is based on a staff ratio of 3:5, as approved by the Autism Advisory Council. Professional time is allocated for both direct service and inservice/consultation activities.

The contrast between the costs of a community-based program and a state-operated residential program are exemplified by the following data based on information furnished by the Department of Mental Health and Developmental Disabilities:

Range of Costs	
Institutions for developmentally disabled children	20,000 - 30,000 (approx.)
Average Costs	
Institutions for mentally ill children	41,025 (approx.)
Institutions for developmentally delayed children	26,056 (approx.)
Community-based program	
Regular School Day	11,091
Extended School Day	16,011
Year round program and extended school day	16,600 - 19,900 (approx.)

It should be noted that none of the state institutions included in these cost approximations provides programs for autistic children.

PERSONNEL

Certified teacher: The assumption is that an experienced MA level teacher fills this position. A BA level teacher's salary would be reduced by approximately $2,000, to $12,000.

Trained aide: Aides are generally hired by the hour. A forty week school year multiplied by a 30 hour week indicates a total of 1200 hours per year. The $6500 annual salary is based therefore, on an hourly rate of $5.41. Because of their important function as a primary therapeutic agent with the children and the necessity of their being trained to work in full partnership with certified teachers, salary scales would theoretically relate to their responsibility and function. An annual salary above the minimal wage scale should reduce turnover and better assure a more permanent corps of trained teacher aides.

Communications specialist: Lack of any meaningful communicative skills is one of the most critical and universal deficits of autistic children. Their progress in all areas depends heavily on their developing some method of communication. Therefore, a communications specialist experienced in working with the population is a vital member of the staff component.

Other Therapists: In order to provide the spectrum of psycho-educational strategies that will successfully address the problems of the disability, additional therapeutic hours are necessary. Depending on the core staff complement and the community's resources, additional personnel to fill the "Other Therapists" category may be:

Occupational Therapist: By virtue of their training and experience, occupational therapists provide skills in assessment and remediation that are intrinsic to presumed neurological dysfunction such as deficits in sensorimotor integration, problems in encoding, and difficulties in stimuli discrimination.

Music Therapist: Frequently music is the only medium to which the autistic child responds. Music is useful therapeutically as a means of quieting a child, to gain his attention, as a precursor for speech development, and may serve as a particularly successful reinforcer in establishing desired behavior and responses.

Therapeutic Recreation Specialist: For the autistic child, physical education and recreation may be as important as the academic program. Therefore, evaluation of the individual

child in implementing a prescriptive physical education program is critical to the total educational intervention. Therapeutic recreation will address areas of gross and fine motor development, provide a mechanism to develop social interaction, provide a means of experiencing some success in developing skills, and may be therapeutic in correcting an underlying neurophysiological aberration. Recreational activities are particularly important as a substitute for self-stimulating or destructive behavior. Furthermore, for the major segment of their life span, the autistic population, by the very nature of their disability, will generally have many hours per day of space to fill up. Development of leisure/recreation skills is therefore critical, particularly since established physical recreation skills are especially helpful in maintaining developmental level and avoiding regression into apathy.

Social Worker: Ten hours per week (two hours per child) are allocated to social work services. In order to achieve maximum benefit from the classroom program, there must be a close working relationship between school and home. Because each family is unique, it is important that there be an understanding of the family composition, its unique capacities and constraints, and how these factors impinge on the individual education program. Families need to understand and to carry out the management system employed in the classroom. It is equally important that the staff persons understand the family's experience as primary caretaker and utilize this knowledge as they work toward mutually agreed upon goals. Without reciprocal respect and cooperation, the success of classroom procedures is significantly diminished, and the procedures themselves may be counterproductive to those utilized in the family setting.

Psychologist: Allocation of the psychologist's time commitment is arbitrary. The diagnostic/evaluation process, if it takes place at the beginning of the school year, will require a heavier time commitment at that time than in the ensuing weeks. The psychologist's contributions to the individualized educational plan will also require more time initially. As the year progresses, there should be a reduction in the hours of psychologic services, regulated primarily by the need for consultation and participation in ongoing staff training.

Medical/Psychiatric Consultation: The assignment of two hours per week to this component is somewhat arbitrary. Individual children may require extensive evaluation by various medical specialists and some children and families will best be served by ongoing psychiatric care as a related service. Under PL 94-142 provisions, the cost of a medical evaluation may be borne by the school system, and psychiatric care as a component of the IEP is a fundable related service.

BUDGET -- EXTENDED SCHOOL DAY

An after hours school program should be flexible in order to accommodate the needs of children whose chronologic and developmental age levels encompass a wide span. Although staff ratios may be somewhat reduced, the primary personnel difference may be in the kinds of staff skills required. Younger children may nap part of the time. Some children may take field trips. Physical recreation activities, arts and crafts opportunities, and unstructured play activities should be available in some scheduled sequence.

It is important that there be some provision for continuity with the regular school day program. One way of providing continuity is to arrange for employees who work on a staggered schedule. For instance, the use of the same teacher's aide from 11 a.m. to 5 p.m., starting the work day in the classroom and continuing in the after school program would reduce the number of different persons to whom the child must adjust. The aide's knowledge of the child and of the therapeutic program would also be invaluable in maintaining consistency and in insuring communication between the school and the after hours program.

In the proposed budget, the social worker's time is split, allocated 25% to the regular school day and 75% to the extended school day. This schedule is predicated on position function rather than on professional discipline per se. The primary intent of the position allocation is to provide a bridge between school and family. A functional job description would include the following duties:

> Participate and contribute to team activities including student's initial and ongoing assessment; implement parents' participation in child's educational/treatment program; provide home training and consultation, as needed; provide leadership to formation of parent groups and continued activities as needed; serve as a liaison person among educational, home, community, and any other program components impinging on the effectiveness of the student's educational/treatment plan.

Program and staffing for the extended school day should be enriched by the inclusion of practicum students and volunteers. The extended school day program is particularly well-suited to early experiential learning for potential special education teachers, psychologists, and social workers, as well as music, communications and recreational specialists.

SUMMER PROGRAMS: SCHOOL PARTICIPATION

Depending on the community's resources and its level of service development, various models of providing year round programs are possible. The following models are not exhaustive. The important fact is that autistic children require year round programming.

Option I

Public or private educational facility provides program for eight weeks. Costs are prorated at 20% of the regular school year's cost.

Program cost	$11,091
Per pupil cost	2,218

Option II

Parks and Recreation agency provides eight week summer day camp programs. Educational facility provides one full-time consultant and transportation.

Personnel cost	$2,000.00
Transportation	1,000.00
Program cost	$3,000.00
Per pupil cost	600.00

Option III

Residential camp is provided for portion of summer weeks. Various appropriate sources such as Title XX, Parks and Recreation, University Therapeutic Recreation Departments, special DD grant mechanisms, etc. would assume costs in some funding mix. Costs for educational providers would be adjusted depending on program content and length.

AUTISM STUDY SUMMARY

In 1978-1979, the Department of Specialized Educational Services of the Illinois Office of Education and The Governor's Planning Council on Developmental Disabilities jointly sponsored an autism study. The purpose of the study was to examine the current system of services to autistic individuals, to identify service deficits and gaps, to delineate a comprehensive continuum of services to autistic persons from birth through adulthood and to recommend those actions necessary to implement the proposed system.

Structure The Department of Specialized Educational Services hired a staff person to conduct the study and the Governor's Planning Council provided funds for travel, consultation, printing, and extraordinary secretarial services (DSES provided normal clerical support services).

An Advisory Council was established to provide direction to the project, to serve as resource persons, and to review documents emanating from the study. Council membership represented parents, professionals, state agencies and geographic diversity.

Methodology The project coordinator made site visits to public and private programs within the state and to a limited number of outstanding programs outside the state to determine administrative structures, staffing patterns, personnel qualifications, program content, program philosophy, problem areas, and the strengths and weaknesses of various service delivery models.

The coordinator reviewed applicable legislation and rules and regulations implementing significant legislation. Meetings were held with representatives of code agencies to ascertain their relationship to the existing system of services. Regional Directors of the Department of Mental Health/Developmental Disabilities were interviewed or requested to respond to a mailed questionnaire relative to services to autistic persons.

There was an extensive review of the literature in the field as regards etiology, diagnosis, remediation, vocational needs, residential programs and current research. National leaders in the field were contacted in person, by telephone and by mail to acquire information about legislation, education, and residential programming.

Throughout the course of the study, administrative staff of both the Department of Specialized Educational Services and the Governor's Planning Council provided both support and information necessary to conducting the study.

Results of the Study The final product of the study is a document organized according to the requirements of the proposal, describing the current system, identifying strengths and weaknesses within the system, discussing some alternative methods used in other parts of the country (when applicable), defining problem areas, and making recommendations toward their solution.

Document Content

1. Description of the Population

Despite increased research efforts of the past ten years, no specific cause for autism has been determined. Because of the results of previous efforts, current etiological studies are primarily focused on bio-chemical research and disorders of the central nervous system.

There is general agreement that the autistic syndrome constitutes a unique disability characterized by disturbances in perception, disturbances of developmental rate, disturbances of relating, disturbances of speech and language, and disturbances of motility.

Disturbances in perception result in bizarre behaviors such as processing information by smelling and touching in preference to seeing and hearing. Particular problems in cross modal processing are typical.

Disturbances in developmental rate are evidenced, for example, by broad discrepancies among motor skill development, language skill development, and social skill development.

Disturbances in relating are of particular significance to diagnosis, remediation and life time planning. They are apparent in the failure of the infant to develop normal bonding patterns, the child's preoccupation with objects rather than with human beings, and the failure to develop reciprocal social relationships in even the highest functioning autistic individual.

Disturbances of speech and language are evidenced by mutism (25-50%), inappropriate use of language, and failure to utilize non-verbal methods of communication.

Disturbances of motility are apparent in the typical hand flapping, rocking and other characteristically stereotyped and perseverative body activities. In the most severely afflicted, repetitive, self destructive actions pose particular problems.

Lack of diagnostic expertise as well as adherence to previous theories of psychogenic causation (fully discredited in the light of current research) contribute to the difficulties

of identifying the population in Illinois and elsewhere. Exclusion of the disability from data retrieval precludes identification of Illinois' population; placement decisions made on the basis of funding/administrative requirements also make identification of the population difficult.

Applying validated prevalence rates to Illinois' population results in establishing a probable target population of 1,000 children between the ages of six and eighteen and a 5,000 total population of classical Kanner syndrome autistics. Defining a population exhibiting the primary handicaps which respond to recommended intervention procedures increases the number of school age childrenin Illinois requiring specific programming to 4,500 and the total population needing service to 22,000.

2. Current Service System

The current service system in Illinois has been affected by the move toward de-institutionalization and by the passage of P.L. 94-142.

Diagnosed as mentally ill or mentally retarded, most autistic persons were formerly institutionalized at an early age. They were rarely served in public school settings or in community-based mental health settings. As the institutional population declined, autistic children remained somewhat longer in the community and were frequently enrolled in day programs for the mentally retarded with an eventual national institutionalization rate of 97%.

Because of its low incidence and because of the complexity of the disability, many autistic children attend private day care rather than public school programs. Generally these are programs for the mentally retarded or the emotionally disturbed. Rimland School in Evanston, and the Illinois Center for Autistic Children in Fairview Heights are the two private programs identified as providing programs specifically and exclusively for autistic children. Some autistic children are also placed in out-of-state residential programs.

The kinds of evaluations required and the kinds of programs and related services necessary to adequately address the needs of autistic children overlap the traditional areas of the mental health service delivery system. Contradictions between federal categorical definitions, as well as policy and structural contradictions among state and

federal legislation contribute to the difficulties of financing and providing a comprehensive continuum of services. Lack of public and professional awareness of the disability compounds the difficulties.

Parents of autistic children universally recite a saga of frustration and discouragement, including misdiagnosis, a lack of family support services, and an absence of temporary or permanent residential programs. Perhaps a dozen public and private educational programs in Illinois are theoretically and operationally excellent. Except as the public school system is required to provide an education for all handicapped children, there is no one agency addressing the needs of this severely and profoundly handicapped population.

3. Prevention

   Inasmuch as the causes of autism remain obscure, there are no specific primary preventive measures that can be applied. Support for research, especially that of the Institute for Neurological Diseases and Strokes, is, however, important so that the reasons for autism can be established. As secondary preventive measures, early diagnosis, preschool education, competent psychoeducational interventions, pre-vocational and vocational evaluation and training, and leisure and recreation opportunities are necessary to prevent or modify life time dependency.

4. Preschool Education

   Early diagnosis of autism in order to institute methods of symptom control, stimulate developmental progress, engage parents in programs of behavior management, provide ongoing diagnostic assessment, and provide family support services are necessary. Without these services, the children and the families experience the full catastrophic impact of the disability.

   Because the symptoms are less visible than those of other physical or cognitive impairments, the diagnosis of autism is frequently delayed and the behavioral and educational deficits exponentially increased.

   The failure to generalize learning and to maintain gains made during an academic year make it imperative that preschool and school age children be provided year round programming.

5. Education for the School Age Child

The physical location of programs serving autistic children in Illinois does not seem to be relevant to the quality of the program offered. The personal characteristics of the staff, the competency of the staff, administrative leadership and support, and the quality of the professional/parent relationship appear to be significant to the success of the educational programs.

The cost of providing adequate staff, equipment and instructional materials is probably higher than that required of any other program. A program cost analysis based on provision of services to five autistic children with a complement of three full-time staff equivalencies results in a per pupil expenditure of $11,000 for a regular school day and $16,000 for an extended school day, year round.

The length of present school days and school sessions contributes to the high institutionalization rate of autistic children. The children regress over the summer. Mothers cannot take a job. There are no trained babysitters available — nor many untrained sitters.

Because this is a disability that does not fit neatly into any service category, but rather manifests symptoms characteristic of a developmental disability, of mental illness, and of a specialized educational need, the costs of providing services should be shared in a rational and equitable manner.

Across the country and in Illinois, it is the exception rather than the rule for the university system to provide adequate preparation for teachers, psychologists or social workers in the field of autism. The subject is generally minimally addressed and the information provided is frequently out-dated.

6. Residential Programs

Currently 97% of autistic persons are institutionalized. Yet Illinois has no residential program specific to the needs of autistic children or adults. Families have the choice of maintaining the autistic person at home, frequently to the detriment of the whole family, or of institutionalization. A range of residential options including levels of respite care, trained homemakers, leisure and recreation programs, summer camps, training homes, foster homes, and sheltered living can ameliorate the impact of the disease on the family,

delay institutionalization, and offer the realistic expectation that some proportion of autistic adults will lead independent and productive lives.

The mission of the Department of Mental Health/Developmental Disabilities requires that each person needing services receives treatment provided in the least restrictive environment possible. The record of service to autistic persons belies this statement.

Title XX, grants to States for Services (P.L. 93-647) has among its goals, provision of services designed to assist income eligible persons and their families in achieving economic self support to prevent, reduce or eliminate dependency as well as preventing or reducing inappropriate institutional care. Yet there is no allocation of funds, nor stated plan that recognizes the urgent needs of these highly vulnerable individuals and their families.

7. Autism Service Center

To address the deficits in diagnostic expertise, lack of trained personnel across all disciplines, the lack of resource expertise, the paucity of educational curricula and materials, and the lack of residential resources, it is proposed that appropriate agencies engage in the development of Autistic Service Centers, located in the northern, central, and southern parts of the state.

The Autism Advisory Council endorses a second year's funding to begin implementation of the recommendations resulting from the study with priority assigned to developing residential services as conceptualized by the Autism Service Center proposal.

SUMMARY OF TITLE XX PROVISIONS

Disbursement of Title XX funds allocated to the State of Illinois must comply to the federal guidelines. The five essential guidelines, the criteria, as it were, which govern the state's Title XX plan are:

1. Achieving or maintaining economic self-support to prevent, reduce or eliminate dependency;

2. Achieving or maintaining self-sufficiency, including reduction or prevention of dependency;

3. Preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interest; or preserving, rehabilitating or reuniting families;

4. Preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care; or

5. Securing referral or admission for instituional care when other forms of care are not appropriate or providing services to individuals in institutions.

Each state must designate an agency to be the administrative agent for Title XX funds. In Illinois, the Department of Public Aid is the administrative agent for the Title XX funds.

In order to distribute funds in an efficient manner, the Department of Public Aid contracts with fourteen state agencies that constitute the Title XX network. The fourteen agencies may then subcontract with either private or public entities to provide stipulated services.

Under the provisions of the federal law, these services must be budgeted and treated as though they were paid for 100%; reimbursement to the state follows at a 75% rate.

Under Illinois law, any monies accruing to the Department of Public Aid must be placed in the general revenue. This means that for all these services provided a budget is drawn up based on general revenue funds. The 75% federal reimbursement goes back into general revenue funds.

The fourteen agencies who comprise the Title XX network are:

1. Department of Public Aid
2. Department of Children and Family Services
3. Department of Mental Health and Developmental Disabilities
4. Department of Corrections
5. Department of Aging
6. Department of Transportation
7. Department of Public Health
8. Department of Veterans Affairs
9. Illinois Commission on Delinquency Prevention
10. Dangerous Drugs Commission
11. University of Illinois Division of Services for Crippled Children
12. Illinois Office of Education
13. Division of Vocational Rehabilitation
14. Illinois State Scholarship Commission

The role of the Department of Public Aid is to plan and administer the statewide Title XX service program and also to provide certain monitoring activities related to the contracts made with the agencies listed above.

Most of the services require income eligibility. However, there are certain services provided without regard to income. Generally, under the federal rules and regulations, services may not be provided to families who exceed 115% of the median income of the state. For example, a family that has four members may have a gross income of $22,236 and be eligible for Title XX services; however, the family must be charged a sliding scale if their income exceeds 80% of the median income. For a family of four, 80% of the median income is $15,469. My understanding is that the agency delivering the services establishes what fees will be charged for those service recipients whose income exceeds 80% of the median income. My understanding further is that those fees accrue to the service providing agency.

Seven services that are not related to income are information and referral, protective investigation and assessment for adults, and protective investigation and assessment for children; that is the extent of the services that may be delivered without regard to income.

There are some particular services that are being delivered that have particular relevance to our planning for services to autistic individuals. The first one of these is day care for children. In the fiscal '79 Title XX plan, day care services for children are provided by the Department of Public Aid, the Department of Children and Family Services, and Illinois Office of Education. The definition of day care for children includes direct care including recreation and education, transportation to and from day care and related activities, technical assistance to and training of child care staff, and physical examinations, including immunizations. My judgment would be that this category may be useful to us both in providing extended school day programs and also in providing recreation programs. The restriction is that there cannot be a direct grant application for these services; that is, the application for such services must be umbrellaed under one of the agencies that is a participant in the Title XX network.

A second component funded in the 79 plan is day training for special needs. The agency providing that service is the DMH/DD.

A third program that may be relevant to our adult population is education and training. That is provided under the 79 plan by Department of Public Aid, Division of Vocational Rehabilitation and the Illinois Office of Education.

Another service that is relevant to our planning is information and referral. More of the agencies in the network provide that service component than any other component. Information referral is provided by DPA, ISSC, DCFS, CDP, DSCS, DDC, DMHDD, DVA and DPH.* The Title XX plan allocated 7,801,000 to this activity in fiscal 79.

A further service provided in 79 that may be relevant to our planning is out-patient treatment. The agency delivering that service is the Department of Mental Health and Developmental Disabilities.

Another service that is funded in 79 is rehabilitation and training for handicapped children; that is provided by the Department of Children and Family Services. It is defined as residential care and rehabilitative activities to meet the special needs of sensory and/or orthopedically handicapped children when such activities are not generally available in the common school system. (There are some subparts that further define that service).

*See list of agencies network for identification.

Another service that may be relevant to our planning is residential child care and treatment, provided in FY 79 by DCFS and by DMH/DD.

An additional service is residential treatment defined as: community based care and supportive activities provided in a planned group living program designed to normalize living conditions and to provide the opportunity for sheltered or competitive employment in a community for developmentally disabled and/or mentally ill adults who are able to live outside an institution. That is being provided in FY 79 by DMH/DD.

Another service currently funded applicable to our planning is social adjustment and rehabilitation. That is defined as direct interaction between an advocate, monitor, or counselor and an individual family or group providing purposeful therapeutic assistance in coping with personal problems and improving social functioning. It may include for instance, participatcn in a camping program, medication supervision and diagnostic assistance if it is a subordinate part of the service; room and board may be included as an integral part but subordinate part of the service but for a period of not more than six consecutive months in any one placement. The agencies providing this service in FY 79 are Department of Aging, Department of Corrections, DMHDD, DPA, DCFS, and the Commission on Delinquency Prevention. The allocation for that service out of the general revenue funds for FY 79 is 11,895,000. Those seem to be essentially the programs that are being funded in 79 that may be applicable to us.

Each individual is not necessarily Title XX eligible. One of the ways of assessing eligibility is to determine in aggregate numbers across the state, on a group basis, whether 75% of the clients being served are eligible. In practice this means that the sampling is not done facility by facility. For instance, there may be a program funded where there are no eligible clients whereas another program may have 98% eligible clients. This kind of information is relevant to allocating Title XX funds inasmuch it is presumed that (if you look at the population of the state as a whole) for that particular service, 75% of the people receiving that service are in fact Title XX eligible.

SELECTED ANALYSIS OF TITLE XX FUNDS

Information and Referral: There are no income restrictions for individuals receiving this service. Its purpose is to help individuals "gain access to appropriate service".[1] A greater number of agencies (9 out of 14) comprising the Title XX network provide this service than any other--a natural phenomenon inasmuch as information and referral is an intrinsic function of any human service agency. Information and referral services are characteristically brief; any extended contact presumes that the agency has shifted to providing its primary function such as outpatient treatment in a community mental health clinic or a child protective service in a Department of Children and Family Services agency.

Follow-up is included in the Information and Referral component as are public information efforts as well as outreach services to specific populations.

The following analysis shows the varying costs of providing this component by participating agencies. The total amount of money allocated is $7,801,300.

Provider Agency	Number to be Served	Cost	Cost ÷ Number to be served
DPA	32,000	$ 166.6	$ 52.06
ISSC	92,924	175.6	1.89
DCFS	25,000	3,961.8	158.47
CDP	239,000	1,135.7	47.74
DSCS	7,200	133.4	18.53
DDC	3,336	55.1	16.51
DMHDD	5,200	1,083.1	208.29
DVA	180,000	390.0	2.17
DPH	18,000	700.0	38.89

Source: Title XX Plan for Illinois, FY 78-79

[1]Comprehensive Annual Services Plan: Title XX, July 1, 1978 - June 30, 1979. II. 27

Type and Purpose of Assistance	Authorizing Legislation	Appropriation Fiscal Year 1978	Who May Apply	Where to Apply
Child Development, Child Welfare Research and Demonstration grants: research and demonstration projects in the area of child and family development and welfare.	Social Security Act as amended, Title VI, Part 15	16,700,000	Public or other non-profit institutions of higher learning-other nonprofit agencies engaged in research	Grants coordinator HEW P.O. Box 1182 Washington, D.C. 20013
Community Education Program: to establish and improve community school programs and operate community education programs.	Elementary and Secondary Education Act, 1974 Special Projects Act, Sec. 405	3,553,000	State and local education agencies, institutions of higher learning.	O.E. Application Control Center
Community Service and Contuining Education: to strengthen higher education capabilities for helping communities solve their problems and to bring continuing education opportunities to adults.	Higher Education Act, Title VIII.	15,000,000	Higher Education Institutions.	O.E. Bureau of Higher and Continuing Education.
Comprehensive Employment and Training Program: job training and opportunity for disadvantaged, underemployed and unemployed. May also provide handicapped individuals with supportive services such as transportation and health care.	P.L. 93-203 as amended with Title VI.	8,346,000,000 (approx.)	States, units of local government with population of 100,000 or more.	Department of Labor
Developmental Disabilities Basic Support: to assist states in developing and implementing a comprehensive and continuous plan to meet the needs of developmentally disabled persons.	Developmental Disabilities Services and Construction Act of 1970 as amended by PL 94-103.	33,058,000 (approx.)	State Agencies	Governor's Planning Council on Developmental Disabilities, 222 So. College, Springfield, IL 62707
Developmental Disabilities Special Projects: partial support for improving quality of service to DD persons including public awareness, new or improved service techniques and delivery, provision of technical assistance—usually projects of national significance.	Developmental Disabilities Services and Construction Act of 1970 as amended by PL 94-103	19,567,000 (approx.)	States, political subdivisions, other public agencies and nonprofit organizations.	HEW Regional Office
Foster Grandparents Program: to provide an opportunity for low-income persons age 60 and over to render person-to-person service in health, education, or related settings to children having exceptional needs.	Domestic Volunteer Service Act of 1973, PL 93-113, Title II	334,900,000	Any public or non-profit private agency, including state and local governments.	ACTION Regional Office or Older American Volunteer Programs 806 Connecticut Ave. N.W. Washington, D.C. 20525
Handicapped Regional Resource Center: to establish regional resource centers that advise and offer technical services to improve education of handicapped children	Education of the Handicapped Act, Part C, Section 621 Section 621	9,750,000	Higher education institutions, state education agencies or combinations including local education agencies.	O.E. Bureau of Education for the Handicapped.

Type and Purpose of Assistance	Authorizing Legislation	Appropriation Fiscal Year 1978	Who May Apply	Where to Apply
Improvement of Post Secondary Education: to aid post secondary reforms in curriculum development, teaching, and administration.	Education Amendment of 1976.	12,000,000	Post Secondary institutions and related organizations.	Fund for the Improvement of Post secondary education, office of Assistant Secretary of Education.
Maternal and Child Health Research: RESEARCH PROJECTS RELATED to maternal and child health.	PL 86-778, Section 512, 42	Average award 174,310,000	Public or non-profit agency	Regional HEW Office
Medical Assistance Program: to provide financial assistance to states for medically needy, persons who except for income and resource would be eligible for cash assistance.	Social Security Act as Amended, Title XIX.	11,816,000,000	State and Local Welfare Agencies	Regional Medicaid Directors
Personnel Training for the Education of the Handicapped: to prepare and inform educators of handicapped children and to ensure an adequate supply of personnel through preservice and inservice training.	Education of the Handicapped, Part D.	43,375,000	State education agencies, higher education institutions, and appropriate nonprofit agencies.	O.E. Bureau of Education for the Handicapped.
State-supported School Programs for the Handicapped: to strengthen programs for children in state-operated and state-supported schools.	Elementary and Secondary Education Acts, Title I, Sec. 12	121,590,937	Eligible State Agencies	O.E. Bureau of Education for the Handicapped

BILL OF RIGHTS FOR AUTISTIC CITIZENS

Whereas, the universal declaration of human rights, adopted by the United Nations, proclaims that all of the human family, without distinction of any kind, have equal and inalienable rights of human dignity and freedom; and

Whereas, the declaration of the rights of the child, adopted by the United Nations, proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education and care required by his particular condition; and

Whereas, the American Declaration of Essential Rights and Duties of Man affirms that "all persons are equal before the law", that "every person has the right to social security which will protect him from the consequences of any disabilities arising from causes beyond his control that make physically or mentally impossible for him to earn a living", and that "every person has the right to be recognized everywhere as a person having rights and obligations, and to enjoy the basic civil rights," and

Whereas, the worth of a civilization is judged by how that civilization treats its handicapped members; and

Whereas, it has become the stated belief of all civilized nations of the world that all persons, without distinction or unreasonable exception are naturally possessed of equal rights and privileges; and

Whereas, it has been long known that all autistic citizens can be helped by ameliorative services including education and training, and that many are capable of leading full and productive lives when afforded appropriate services combined with the right to enjoy the precious opportunities and freedoms that others take for granted; and

Whereas, even in an era of acute sensitivity to the plights of racial and religious minorities, archaic and misguided customs, laws and practices have regularly denied and abridged to the handicapped certain rights and privileges which, taken together, contribute immeasurably to the individual dignity and worth of every person; and

Whereas, society, individually and collectively, benefits proportionately to the opportunities afforded all persons to fulfill their own maximum potential;

Now therefore, be it resolved by the National Society for Autistic Children that:

ARTICLE I. The autistic citizen has the right to enjoy the respect of others. The dignity and potential of each individual must be respected.

ARTICLE II. The autistic person has the same rights as other citizens of the same state and same age.

ARTICLE III. The autistic person has a right to proper protection under the law and a right to proper treatment, medical care and physical restoration and to such education, training, habilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. No mentally handicapped person should be deprived of those services by reason of the costs involved.

ARTICLE IV. The autistic person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation.

ARTICLE V. The autistic child has a right to live with his own family or with foster parents, to participate in all aspects of community life, and to be provided with appropriate leisure time activities. If care in an institution becomes necessary it should be in surroundings and under circumstances as close to normal living as possible. The autistic adult has the right to adequate housing.

ARTICLE VI. The autistic person has a right to a qualified guardian when this is required to protect his personal well-being and interest.

ARTICLE VII. The autistic person has a right to protection from exploitation, abuse and degrading treatment. If accused, he has a right to a fair trial with full recognition being given to his degree of responsibility.

ARTICLE VIII. Some mentally handicapped persons may be unable, due to the severity of their handicap, to exercise for themselves of all of their rights in a meaningful way. For others, modification of some or all of these rights is appropriate. The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on evaluation of the social capability of the mentally handicapped person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities.

ARTICLE IX. The autistic citizen has the right to treatment by society in accordance with **THE NORMALIZATION PRINCIPLE,** as described by Bengt Nirje in **"Changing Patterns",** including making available to the mentally handicapped patterns and conditions of everyday life which are as close as possible to the normal patterns and conditions of the mainstream of society.

ARTICLE X. The customs, laws and practices which discriminate against the mentally handicapped must be ended and those customs, laws and practices which enhance the ability of the mentally handicapped to function to the maximum of his capability and to contribute to society must be encouraged.

ARTICLE XI. The autistic citizen has the right to protection against legal discrimination or abuse in any form because of his condition.

ARTICLE XII. The autistic child has the right to the earliest possible ameliorative intervention.

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